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The role of significant others in the health behaviours of patients with Type 2 diabetes

THE ROLE OF SIGNIFICANT OTHERS IN THE HEALTH BEHAVIOURS OF PATIENTS WITH TYPE 2 DIABETES

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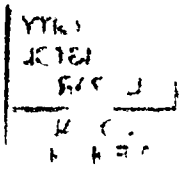

ABSTRACT

Previous research has demonstrated that the successful management of type 2 diabetes is dependent on the patients' social environment, in particular, the role of significant others. Therefore, the focus of this research was to explore the illness beliefs of patients with type 2 diabetes and their partners in a prospective study. The theoretical framework for the research was guided by the self-regulatory model of illness behaviour (Leventhal et al, 1984) which asserts that individuals conceptualise illness around 5 'core' dimensions regarding the *control, consequences, course, identity* and *cause* of their condition. These 'illness representations' describe the underlying differences on which individuals differ with regard to their illness.

In particular, the extent that patients and partners share representations of diabetes was explored in relation to the patients' adaptation and self-management of the condition. A total of 164 patient-partner dyads were recruited and followed-up at 12 months later. The illness representations of patients and their partners were assessed with diabetes-specific measures. Patients' self-management behaviours were assessed by self-report measures of adherence with diet, physical activity and medication at both time-points and objectively with a single measure of glucose control (HbA1c) at 12 months. In addition, marital satisfaction and psychological morbidity were assessed at both time-points. It was found that patient-partner dyads, generally, held similar representations of diabetes. In addition, logistic regression analyses demonstrated that partners' diabetes representations were influential in the extent of patients self-management behaviours, and levels of psychological morbidity after the influence of patients' representations, past behaviour, and demographic and clinical variables.

The findings are discussed in the context of previous research examining illness representations in chronic disease, the implications for the self-regulatory model of illness behaviour and future behavioural interventions to improve the self-management behaviours of patients with type 2 diabetes.

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Love and thanks to my family; Kate, Ines and Mara.

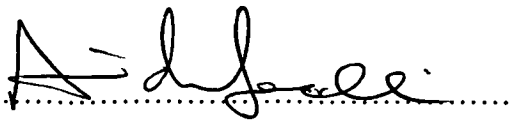
This thesis is dedicated to the memory of my father;
Francis George Searle (1914 - 2002).

AUTHOR'S DECLARATION

I declare that the work in this dissertation was carried out in accordance with the regulations of the University of Bristol. The work is original except where indicated by special reference in the text and no part of the dissertation has been submitted for any other degree.

Any views expressed in the dissertation are those of the author and in no way represent those of the University of Bristol.

The dissertation has not been presented to any other University for examination either in the United Kingdom or overseas.

SIGNED: 

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CHAPTER 1: THE SOCIAL CONTEXT AND THE MANAGEMENT OF DIABETES

1.1. Introduction

The present thesis aims to explore the role of significant others in the health behaviours of patients with type 2 diabetes. Before introducing the theoretical framework used to facilitate this enquiry, the extent and nature of how a diabetic patients' social environment impacts on disease management is examined. Therefore, this introductory chapter focuses on the importance of the social context in relation to patients' efforts to manage diabetes with regard to their health behaviours and control of blood glucose. In particular, the chapter will focus on the construct of social support and its relationship with adherence to treatment recommendations in patients with diabetes

A critique of social support and its measurement precedes the review of empirical studies examining the construct. There are also a number of points and issues regarding treatment adherence that are addressed before reviewing the empirical literature examining the role of social support and diabetes. These include; the prevalence and consequences of non-adherence in chronic disease, the distinction between intentional and non-intentional adherence, and the measurement of adherence. Finally, the ongoing debate regarding the terminology used to describe patients' fulfilment of treatment recommendations is also addressed.

What is type 2 diabetes?

Type 2 diabetes (non-insulin dependent) presents as a spectrum of metabolic abnormalities characterised by prominent insulin resistance and relative insulin deficiency. It accounts for about 90% of all cases of diabetes, tending to emerge in mid to late adulthood. The major risk factors for diabetes include a family history of diabetes, obesity (BMI > =27 kg per m ^{2}) age (> = 45 years),

hypertension, and high cholesterol levels. There is a progressive increase in the world-wide prevalence of type 2 diabetes. This increase is primarily the result of lifestyle changes, and in particular the steady rise in the prevalence of obesity (Amos et al, 1997, WHO, 1997). Finally, the prevalence of type 2 diabetes is projected to double by 2010 and is also accelerating in the younger population (*ibid*).

Consequences of type 2 diabetes

The longer the duration of diabetes the greater the likelihood of developing symptoms and signs of degenerative complications. The consequences of poor management of type 2 diabetes can be severe. Complications related to diabetes include blindness, amputations, and diseases of the kidneys, heart and central nervous system (Kaplan & Hartwell, 1987). The treatment of diabetes and its complications also constitutes a huge financial burden accounting for around 5% of the UK National Health Service budget (Leese, 1991).

Management of type 2 diabetes

Apart from being a serious chronic illness and social problem, the patient with type 2 diabetes has the principal responsibility for the management of their illness. In particular, the daily management of diabetes involves eating regular healthy meals, taking physical exercise, self-testing blood glucose levels and, for many patients, taking medicine. The goal of this combination of tasks is to maintain glucose levels within a target range - by achieving tight blood glucose control the rate of complications decreases (DCCT, 1993; UKPDS, 1998). Self-management not only involves completing such activities but considering the inter-relationships among these tasks and implementing appropriate changes in the daily plan when necessary. However, rates of non-adherence with these behaviours are high, ranging from 30–75% (Paes et al., 1998) and often result in poor disease outcomes (Nicolucci et al., 1996). Indeed, Nicolucci et al speculate that the risk of diabetic complications could be reduced by up to one third, if

such 'avoidable' factors could be removed. Therefore, a major concern in the management of type 2 diabetes is how to encourage adherence with prescribed regimens.

The role of diet

Following a healthy diet is the primary treatment for type 2 diabetes. The goal of dietary intervention is to maintain near-normal glucose and lipid levels; maintain a reasonable body weight; prevent, delay or treat nutrition related risk factors and complications and improve overall health (Franz et al, 1994). However, dietary advice (along with physical exercise) is the most difficult aspect of the treatment regimen for patients to adhere with (Glasgow et al, 1997). An analysis of adherence to diet therapy among patients with diabetes showed that only 20-50% of patients followed dietary recommendations (Savage & Knowler, 1984; Skender et al., 1996). Moreover, Hixenbaugh and Winkley (2001) demonstrated that many patients have difficulty in eating the right type of food (59%), the right amount of food (49%) eating at regular intervals (36%) and maintaining an ideal weight (37%).

The current dietary recommendations for patients with type 2 diabetes are the same as for the general population. It is, therefore, the recommendation of Diabetes UK (formerly British Diabetic Association) to eat regular meals that are;

- low in fat (esp. saturated fat)
- high in fibre
- eat carbohydrates high in starch
- low in sugar

and to:

- eat five portions of fruit and vegetables a day
- reduce salt
- moderate alcohol consumption

In addition, patients are encouraged to achieve /maintain a desirable body mass index (BMI). All newly diagnosed patients with diabetes should receive dietary advice from a State Registered Dietitian and receive additional support from a trained member of their Primary Health Care Team (Avon Health Diabetic Care Manual, 1996).

1.2. Prevalence and consequences of non-adherence

Patient non-adherence with a treatment regimen may seriously undermine the effectiveness of medical care, and may, in turn give rise to poorer clinical outcomes (Haynes et al., 1996). Therefore, adherence with medical regimens is widely recognised as one of the principal challenges in healthcare. Non-adherence amongst patients is more prevalent when the illness is chronic and the treatment recommendations are largely prophylactic (Haynes et al., 1979; Meichenbaum & Turk, 1987). Approximations of the scale of the problem vary considerably, although average estimates of adherence in chronic illness converge at about 50% (Evans et al. 2001; Hulka et al. 1976; Wright, 1993).

A specific consequence of non-adherence is an increase in diagnostic and therapeutic procedures, with subsequent increased health-care expenditure. It has been speculated that the risk of diabetic complications could be reduced by up to one-third if adherence with health behaviours could be improved (Nicolucci et al, 1996). The far-reaching financial and human costs of non-adherence (Lowe et al, 1995) have led to many investigations to seek to identify the determinants of adherence. This work has identified a number of socio-demographic (e.g., age, gender, ethnicity, social class, disease status: Hawthorne et al, 1993; Koskinen et al, 1996; Nicolucci, et al., 1996; Dunbar-Jacob et al. 1995) and psychosocial correlates (e.g., social support, locus of control, health beliefs, psychological morbidity: Fukunishi et al, 1998; Schoenberg et al, 1998; Schwartz et al, 1991), and has led to the development of interventions designed to promote adherence (Epstein & Cluss, 1993, Lustman et al, 1998). However, results indicate that many of these interventions have failed to

generate significant improvements in adherence and treatment outcomes (Haynes et al., 1998). Thus, the understanding of the factors which may influence medication adherence remains inadequate.

It is also acknowledged that many other factors influence adherence to treatment regimens such as the perceived efficacy of the treatment, cost-benefits of adherent behaviour, complexity of the regimen, side effects of medication, psychological morbidity and socio-economic status which have been explored elsewhere in the literature. In addition, issues such as the quality of the practitioner-patient relationship, satisfaction with care, understanding of the condition may also impact on adherence as described in the seminal work of Ley (1982,1988).

Intentional and non-intentional adherence

It is suggested that non-adherence behaviours fall into two broad categories (Horne, 1997). First, 'unintentional' non-adherence occurs when the patients' intentions to take the medication are impeded by barriers such as forgetting, and inability to follow the treatment instructions because of poor understanding, memory or physical problems such as poor eyesight or impaired manual dexterity. Second, 'intentional' non-adherence is when an individual chooses not to follow some or all of prescribed treatment recommendations or when an individual has learned to manipulate or deviate from treatment recommendations that suits his or her lifestyle. Intentional non-adherence is sometimes referred to as "intelligent non-compliance" in acknowledgement of the fact that, from the patient's perspective, it may be viewed as the result of a rational decision. This chapter focuses on intentional or 'intelligent' non-adherence.

Measurement of adherence

Multiple methods of assessment are used in research examining adherence to treatment recommendations including self-report questionnaires and diaries, biological markers, and clinical outcomes. However, there are important issues regarding the measurement of adherence with treatment regimens. Each method reveals somewhat different information about the patient's behaviour with regard to their regimen as well as different reports of adherence. Therefore, the selection of a strategy to measure adherence requires careful attention to the limitations of each method and a well-specified definition of adherence. Indeed, there is a danger that self-report measures of adherence may permit patient over-reporting due to failure of memory or understanding or deliberate omission of the truth to bias findings. Taking medication adherence as an example, when validated against objective measures such as pill counts or biochemical methods, self-report is highly variable in terms of accuracy (Francis et al, 1969). This has been observed across a range of therapies for chronic conditions including medications for hypertension (Rudd et al., 1989) and RA medications (Dunbar-Jacob, 1993). In addition, studies that rely on clinical outcome measures (e.g., blood pressure, HbA1c) may also be unreliable as a patients' condition may improve or deteriorate for reasons unrelated to adherence such as stress (Surwit & Schneider, 1993).

The 'adherence' versus 'compliance 'debate

Finally, there is considerable debate regarding the most appropriate terminology to use when describing patients' fulfilment of recommended health behaviours. Indeed, terms such as 'adherence', 'compliance' and 'concordance' are often used interchangeably in the literature. Some investigators argue that differences between these terms extend beyond semantics. Indeed, Trostle, (1988) asserts that the term 'compliance' is an expression of practitioner's medical authority over patients who are expected to obey without question. Others, such as Eisenthal et al., (1979) argue that 'adherence' is a confirmation of the active, participative role of patients in the management of their care.

Adherence has been defined as.....*'the extent to which the patient's behaviour (in terms of taking medications, following diets or other life style changes) coincides with medical or health advice'* (Haynes, 1979). More recently, 'concordance' has emerged as a term to describe an agreement reached between a patient and a practitioner that respects the beliefs and wishes of the patient determining whether, when and how medicines are to be taken. Although reciprocal, this is an alliance in which health care professionals recognise the primacy of the patient's decisions about taking the recommended medications. While acknowledging such differences in terminology, the term 'adherence' is used in the present thesis and is intended to encompass the definition given by Haynes (1979).

1.3. Social support: An introduction

Much research effort has been invested in the purported beneficial effects of social support on health and well-being. Indeed, empirical evidence suggests that social support is associated with greater adherence with treatment regimens (Levy, 1986). Before examining this work two general models that explain how social support may impact on treatment adherence in chronic disease are introduced. First, the 'main effects' model of social support is considered to be a positive and useful resource such that the benefits are great even when people are not exposed to stressful situations such as chronic illness (Cohen & Syme, 1985). The second model known as the 'buffering' model, suggests that social support may serve as a source of protection (as a buffer) against adverse effects resulting from the presence of a stressor (Cohen & McKay, 1984). Indeed, it is likely that social support may enhance adherence, either directly (through encouragement, reassurance, reinforcement, systematic cues, bolstering of competence, and motivation) or indirectly (by buffering the effect of factors that may impede adherence, e.g., life stress, anxiety and depression). However, this section primarily addresses the literature examining the 'main effects' model of social support in studies with diabetes patients and the role of the spouse in particular. First, however, issues surrounding the measurement of social support are addressed.

Measurement of Social Support

The measurement of social support has been approached in two main ways. One approach conceives of social support in terms of the *structure* of an individual's interpersonal relationships or social network, the other in terms of the *functions* that these relationships or networks serve for an individual. The measurement of social support is based on tools assessing an individual's perception of either the availability of others who provide these functions or the actual receipt of these support functions (Stroebe & Stroebe, 1995). Therefore, 'structural' measures assess the existence or quantity of social relationships (i.e., availability of family and friends), whereas 'functional' measures of social support assess whether interpersonal relations serve particular functions (types of resources). Turner (1992) asserted that the effective measurement of perceived support provides the best lever by which to estimate the relative significance of potentially modifiable social factors for health and well-being. Furthermore, conceptions of available social support are both dispositional and cognitive, whereas conceptions of perceived support are situational and behavioural, involving interaction between individuals (Dunkel-Schetter et al. 1992).

With regard to 'functional' measures, it has been proposed that social support consists of multiple components. Indeed, Schaefer et al. (1981) studied the relationship between social network size and three types of social support; 1. 'tangible' (or 'instrumental'), 2. 'emotional' and 3. 'informational'. The three types of support were examined in relation to stressful life events, psychological symptoms, morale and physical health status, hence recommending the need to study these components separately. 'Instrumental' support consists of behaviours that directly help the person in need (i.e., practical help with work etc). 'Emotional' support involves providing empathy, care, love and trust. Finally, 'informational' support involves providing people with information that they can use in coping with their problems. However,

House and Kahn (1985) also include 'appraisal assistance' which is closely related to 'informational support'. It also involves the transmission of information relevant for an individual's self-evaluation. Finally, Cutrona (1990) added a fifth component, 'social integration', which combines *structural* and *functional* characteristics of support.

A problem with only measuring recipient perceptions of social support instead of the actual support that is given is that such perceptions are not always accurate. Such perceptions are not only based on what the recipient felt was needed versus what was actually given, but what the provider(s) perceived was needed by the recipient. In addition, provider and recipient perceptions do not correlate well. For example, providers may feel that they are giving more than what recipients feel they are receiving (Sarason et al., 1990). Recipients may also be dissatisfied and consider it negative support if the provider encourages behaviours that the recipient does not want to display (Tilden, 1985).

When evaluating social support it is also necessary to consider cause and effect. For example, it may be difficult to determine whether a lack of social support contributed to a problem occurring (e.g., depression) or if the problem was pre-existing in the individual and thus influenced the lack of adequate social support. Researchers have tended to ignore this phenomenon and assume that social support always results in positive outcomes. Also, researchers tend not to examine social support and changes in social network over extended periods of time (Kahn, 1994). Furthermore, support may vary throughout one's life, or even through the course of a stressful life event such as chronic illness. As a result it is difficult to evaluate this cause-effect phenomenon.

Support from significant others

A supportive family environment has been identified as a particularly important source of social support for chronically ill individuals (Moos & Moos, 1986). Furthermore, an early study demonstrated that support provided by the spouse may determine adherence to long-term medical regimens (Doherty et

al.,1983). The authors examined the influence of social support on adherence with hypertensive treatment from the perspective of the participant, the spouse and medical staff members. The authors reported that hypertensive men who had highly supportive spouses were more likely to adhere to their medication regimen than men with less supportive spouses. The health beliefs of the spouse were also related to levels of support provided. Indeed, wives who believed more strongly in the benefits of the therapeutic regimen were more likely to offer higher support to their husbands. This seminal study demonstrated the importance of spousal health beliefs, provision of support and the implications for adherent behaviour.

1.4. Social support and diabetes management

With regard to the topic of the thesis, studies examining the role of social support and marital satisfaction in the management and control of diabetes are reviewed in the following section. These studies are also summarised in Table 2.1.

A search was conducted to locate empirical studies examining the role of the social context in the management and control of diabetes. In particular, the search focused on finding literature examining the 'social support' in the context of treatment adherence in adult diabetic patients. Quantitative studies published in the English language were located through undertaking electronic database searches on 'PsychInfo', 'BIDS', 'Web of Science' and 'Medline'. Further literature was found by hand searching journals and reference lists from relevant journal articles.

Family support in type 2 diabetes

MacLean and Lo (1998) examined expected success in adherence with exercise and diet regimes in 95 patients with type 2 diabetes. The aim was to determine if family support was associated with adherence and intentions to continue to adhere. Family support was assessed with the Perceived Social Support from

Family Scale (Famsup: Procidano & Heller, 1983). The General Health Questionnaire (Goldberg, 1978) was used to assess transient and chronic stress. In addition, variables pertaining to intention, self-efficacy and self-esteem (Self-Esteem Inventory; Rosenberg, 1995) were also evaluated. The results from regression analyses demonstrated that adherence was a function of the capacity to utilise family support, positive attitudes, high self-esteem, absence of stress and acceptance of the challenges of the illness. The importance of good family support, absence of stress, and capacity to take up the challenges of the disease was replicated by Lo (1999) with regard to successful adherence in 146 diabetes patients dependent on insulin.

Overall, the findings of these studies indicate that patients with diabetes who have access to good social support and experience less stress are more likely to engage in adherent behaviours. However, as these were cross-sectional studies it is not permissible to make causal predictions, it is possible that good intentions to adhere attract higher levels of support from the patient's family. It is also reiterated that actual adherence was not measured, instead a measure of the patient's efficacy and intention to comply with the regimen was utilised. Furthermore, no distinction was made between diet, exercise and blood-glucose testing, therefore it cannot be assumed that patients' intend or are able to adhere equally to these management requirements. It is also uncertain to what extent such findings can be viewed as indicators of patients' actual behaviours regarding the successful management of diabetes. It is well documented from previous research that intentions to perform a health behaviour do not necessarily translate into an action been taken. Indeed, it may be that further cognitive activity is required to ensure that intentions are translated into actions (Norman & Conner, 1996).

In a study of 213 insulin-treated patients with diabetes Toljamo and Hentinen (2001) examined the role of social support and adherence to self-care regimens. Social support was assessed with an instrument developed for the study based on the definition of social support provided by House (1981). It consisted of 13

items relating to 'emotional', 'instrumental', 'informational' and 'peer' support from other patients. Adherence to aspects of the diabetic regimen were measured with a 20-item scale covering insulin treatment, diet, exercise and blood-glucose monitoring. Metabolic control was measured with levels of HbA1c taken from patient records. Measures of HbA1c reflects patients' mean metabolic control over the 6-12 weeks preceding measurement and is part of the routine management of patients with diabetes and widely accepted as reliable and valid index of metabolic control (Nathan et al., 1984).

Factor analysis of the adherence to self-care scale revealed two distinct factors: 'flexible self-care' and 'regimen adherent self-care'. These factors were then dichotomised at their median value to give the following four adherence categories: 1) 'regimen-adherent self-care', 2) 'no regimen-adherent self-care', 3) 'flexible self-care' and 4) 'no flexible self-care'. The factor structure of social support was also examined. The items regarding 'emotional' and 'instrumental' support loaded highly on the same factor, and were combined to form a single variable labelled 'emotional and instrumental' support. The remaining variables of 'informational', 'peer', 'negative' and 'financial' support remained intact. Logistic regression analyses were employed to determine predictors of neglect of self-care. Patients who adhered to self-care either flexibly or with strict adherence to the regimen received more social support from family and friends than those who neglected self-care. There were no statistically significant relationships between other types of social support and adherence to self-care. Surprisingly, those who perceived more peer support from other patients with diabetes had worse blood-glucose levels. Getting no 'emotional and instrumental' support was related to neglect of self-care. The authors concluded that adherence to self-care was associated with support from family and friends. In particular, those with 'emotional and instrumental' support from their friends and family adhered better to self-care.

For efficiency in the operationalisation of social support in this study, the type and source of support were combined. However, in so doing, some

information may have been lost; therefore social support may be best assessed with separate measures to capture more accurately the nature of support. A further limitation, is that participants were regular attenders at a diabetes clinic and thus must be considered as having a more responsible approach to managing their disease and may not be 'typical' diabetes patients.

Glasgow and Toobert (1988) prospectively, examined the influence of the social environment in relation to health outcomes in 127 patients with type 2 diabetes. The social environment was assessed with the Diabetes–Family Behaviour Checklist (DFBC), a self-report measure specifically developed to assess social support received from family members for the performance of self-care activities in patients with type 1 diabetes (Schafer et al., 1986). The scale was modified (DFBC-II) for use in a population with type 2 diabetes. Two versions of the DFBC-II were administered; one for the subject and another for the partner or 'significant other'. Four different aspects of the diabetes regimen were assessed (glucose testing, medication taking, diet and exercise). Dietary adherence was also measured with a 3-day food record and subjects were trained to estimate portion sizes and asked to weigh servings of meats and cheeses. Adherence to medication, physical activity, and glucose testing was assessed with a version of the Summary of Diabetes Self-Care Activities scale. It was demonstrated that measures of family support were the strongest and most consistent predictors of a composite measure of adherence in patients with type 2 diabetes. However, the results of this study are tempered by relying solely on self-reports of family interaction. In addition, the process of self-monitoring family interactions may have altered patterns of self-care over the period of study.

The role of social support and self-efficacy (belief in the ability to perform a given behaviour) in the self-care behaviours of 94 patients was assessed in patients with type 1 or type 2 diabetes (Williams & Bond, 2002). The ability to perform behaviours in four regimen areas; blood glucose testing, exercise, eating habits and medication were assessed with a 29-item questionnaire. The

frequency of both supportive and unsupportive family behaviours was assessed with the DFBC (Schafer et al, 1986). Items of the scale addressed blood-glucose testing, diet, exercise, medication, and general regimen adherence. Participants nominated their closest supporter (e.g., wife, husband, daughter) and indicated how often that person assisted in the performance of a given self-care behaviour. Response options ranged from 'never' to 'at least once a day'. Self-care behaviour was assessed with the Summary of Diabetes Self-Care activities scale (Toobert & Glasgow, 1984). The family member nominated as providing the most help with diabetes management was the spouse or partner (n=75, 83% of those with family support). It was demonstrated that self-efficacy was associated with social support and positive diet-related family interactions. In addition, a mediation effect was found for self-efficacy with positive diet self-care support and positive exercise self-care support. However, when the effects of self-efficacy were controlled, social support was no longer a significant independent predictor of self-care. The authors argue that the results support Bandura's (1977) claim that social support is a source of efficacy information but does not affect behaviour directly, thus social support could be an important source of efficacy information among diabetes patients. Although this study showed that the receipt of social support was a predictor of dietary and exercise behaviour, no such relationship was found for medication adherence. This may be a function of using a composite measure of regimen adherence such as the Summary of Diabetes Self-care Scale which may not have been able to differentiate among different aspects of behaviour. Alternatively, if this finding truly reflects the relationship between social support and medication adherence it affirms the view that 'it should not be assumed that because a family member is supportive of a patient's adherence to one aspect of the regimen.....that he or she will be supportive of other diabetes activities' (Glasgow & Toobert, 1988, p. 384)

Social support and gender

It has been observed that social support has differential effects for men and women in relation to health (Antonucci, 1985; Kessler et al., 1985). These effects

have also been demonstrated in type 2 diabetes. In a small and simple study (n= 37), Heitzmann & Kaplan (1984) examined the role of support in relation to blood-glucose control. The patients' social support network was measured by the Social Support Questionnaire (Sarason et al., 1983). The SSQ provides separate scores for *network* size and *satisfaction* with available support.

A single measure of HbA1c was used to assess the extent of control of diabetes The measurement of HbA1c provides a measure of blood glucose control such that higher levels indicate poorer control of diabetes. Groups of high and low recipients of social support were formed by median split and analysis of variance was conducted to determine the effects of gender and social support on levels of HbA1c. It was demonstrated that women were in better control of type 2 diabetes when they were more satisfied with their social support network. In contrast, men were in poorer control when they had high satisfaction with social support scores. However, the social support network scores were not significantly related to glucose control for men and women.

These results were replicated in a prospective study Kaplan and Hartwell (1987) using the Social Support Questionnaire (Sarason et al., 1983). Regimen adherence was assessed via levels of HbA1c. Male patients expressing greater satisfaction with perceived social support exhibited poorer glyceamic control at 18-months follow-up. In addition, women selected spouses as supports only half as often as men did. This study highlighted the complexity of the relationship between satisfaction with social support, network size and gender with the control of type 2 diabetes.

Together, these studies suggest that social support, network size and satisfaction have different functions for men and women with type 2 diabetes. One explanation is that social support serves as a more important buffer of stress for women than it does for men. According to the buffering hypotheses, social support should have greater effects under higher levels of stress. In this study women reported greater worry than men relating to their diabetes and, in

turn, may have a more positive response to high levels of social support. However, it is unclear why diabetes should be correlated with low worry for men but not for women. It is possible that men have a more casual disposition toward their illness and that they receive support for this stance. Alternatively, it could be that a satisfactory support system directly affects behaviours that result in good or poor control of diabetes. For example, networks found satisfactory to women may support behaviours that lead to good control. In contrast, networks satisfactory to men may reinforce lifestyle patterns that are not in the patients' best interests.

Social Support and family functioning

It has been proposed that the family system has a role in the initiation, selection of symptoms, clinical course, use of clinical facilities and adherence to medical treatment in chronic disease (Anderson & Auslander, 1980, Hansen & Hengeller, 1984). The 'family functioning' concept refers to a set of patterns or interactions among members of a family (Epstein et al., 1978). During the course of a chronic disease such as diabetes, adverse interactions may impose an excessive load on the capability for adaptation of the family. Thus, it is suggested that under such circumstances, family functioning may change to 'rigid' control, which may threaten family stability.

Garay-Sevilla et al (1995) examined the role of social support in adherence to diet and medication in patients with type 2 diabetes. Support was assessed in 200 patients with a modified diabetes-specific questionnaire (Ruggiero et al., 1990). Family functioning was evaluated with the modified McMaster model (Epstein et al., 1978). Adherence to treatment was assessed with a seven-item self-report measure concerning daily intake of food, acceptance and adherence to prescribed diet and the patient's interest in keeping an appropriate weight. In addition, medication adherence was assessed with three questions about continuity of intake (e.g., self decided changes of doses). Regression analyses demonstrated that adherence to diet was predicted positively by social support

and disease duration. Social support was also the main determinant of medication adherence. In addition, adherence to medication was lower in patients from families with *'rigid control'* (if permissions for members of the family were seldom given) than those with *'laissez-faire'* (if permissions were almost always granted) type of control or *'flexible'* control (if permissions were frequently obtained).

A rigid control of behaviour within a family may imply decreased adaptation to change, in particular to deleterious changes such as chronic disease in one of its members. In turn, this may favour denial of the disease. It may also enhance the development of conflict with the authority, increasing the denial of the disease resulting in a decrease in adherence. Finally, the results are compromised by a response rate of just 20%. Therefore it is possible that those consenting to participate were naturally more concerned about their condition and consequently exhibited greater adherence.

The marital relationship and blood-glucose control

Trief et al, (2001) examined the relationship between marital adjustment, blood-glucose control and psychosocial adaptation to diabetes. A mixed sample of 78 married patients aged 18-55 years with insulin-treated type 1 or type 2 diabetes (≤ 1year) participated in the study. Marital quality was measured with the DAS (Spanier, 1976). Functional health status was measured with the MOS-SF36 (Ware & Sherbourne, 1992). Diabetes-specific emotional distress was assessed with the Problem Areas in Diabetes Scale (PAID; Polonsky et al, 1995). Finally, glucose control was assessed with a single measure of HbA1c.

Higher levels of marital satisfaction predicted lower scores on the PAID. Marital quality did not predict levels of HbA1c when treated as a continous variable. Thus subjects were divided into three groups; good glyceamic control was defined as ≤ 7.4%, acceptable control was defined as a value between 7.5-8.4%, and poor glyceamic control was defined as HbA1c value of > 8.4%. These figures were based on the findings of the Diabetes Control and Complications Trial which demonstrated that the risk of significant microvascular

complications dramatically increases when HbA1c levels exceed 8.4% (DCCT Research Group, 1988). Due to small numbers 'acceptable' and 'poor controlled' patients were combined for analysis and dichotomised into two groups; HbA1c < 7.4 and ≥ 7.4%. Stepwise regression analyses demonstrated a trend for marital satisfaction measures with the DAS to be predictive of glyceamic control, although the effect just missed statistical significance (p=.056). The authors concluded that marital quality does relate to an individual's adaptation to diabetes with regard to levels of emotional distress. Although a significant relationship was not found for marital satisfaction and HbA1c it is suggested that the marital relationship may be more powerful than general family support in terms of its impact on glyceamic control. Finally, the cross-sectional design prohibits enquiry into causality as it cannot be determined if a poor relationship leads to poor illness adaptation and glucose control or that poor control/adaptation leads to a more problematic marital relationship. Finally, by including patients with both type 1 and type 2 diabetes it is difficult to delineate how support and marital satisfaction differ for these medically defined sub-groups. Indeed, regular insulin administration by patients with type 1 diabetes may pose unique challenges compared with type 2 diabetes patients that are primarily managed by diet.

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Table 1.1 . Summary of studies examining social support or spouse support in the management and control of diabetes.

Author & year	Objectives	Participants	Design & Measures	Findings
Heitzmann & Kaplan (1984)	To determine the relationship between social support, gender and glucose control	37 type 2 diabetes patients 51% Male Mean age: 53 years	Cross-sectional Social Support Questionnaire (Sarason et al, 1983) HbA1c	Women were in better control of type 2 diabetes when they were more satisfied with their social support network. Men were in poorer control when they had high satisfaction with social support scores
Kaplan & Hartwell (1987)	To determine the relationship between social support, gender and glucose control	77 patients with type 2 diabetes 73% female Mean disease duration: 17 years Mean HbA1c: Males= 8.3%, Females=8.9%	Prospective: (18 months follow-up) Social Support Questionnaire (Sarason et al, 1983) HbA1c	Male patients expressing greater satisfaction with perceived social support exhibited poorer glycemic control. In addition, women selected spouses as supports only half as often as men did
Glasgow& Toobert (1988)	To investigate the predictive validity of the social environment with regimen adherence	127 adults with type 2 diabetes 69% female Mean age: 61 years Mean disease duration: 9.1 years Mean HbA1c: 9.35%	Prospective (6 month follow-up) Diabetes Family-Behaviour Checklist Summary of Diabetes self-care scales HbA1c	Family support was the strongest and most consistient predictor of a composite measure of adherence in patients with type 2 diabetes

Author & year	Objectives	Participants	Design & Measures	Findings
Lo (1999)	To determine the role of family support and stress in adherence	146 patients with type 1 diabetes 56% female Age: 46-55 years	Cross-sectional General Health Questionnaire Perceived Social support from family scale	Expected success in adherence associated with good family support and the abscense of stress
MacLean & Lo (1998)	To determine the role of family support and stress in adherence	95 patients with type 2 diabetes Age 46-65 years 56% female	Cross-sectional General Health Questionnaire Rosenberg self-esteem inventory Perceived Social support from family scale	Intentions to adhere were a function of the capacity to utilise family support, positive attitudes, high self-esteem, absence of stress and acceptance of the challenges of the illness
Toljamo & Hentinen (2001)	To determine what type of social support influences adherence and glucose control	213 insulin treated diabetes patients Disease duration: > 1 year 58% Male Mean age: 40 years Mean HbA1c: 8.1%	Cross-sectional Social support scale developed for study measuring 'emotional', 'instrumental' , 'informational' 'financial' and 'peer' support 20-item Self-care scale developed for study measuring insulin treatment, diet, exercise, blood glucose monitoring and responsibility HbA1c	Patients who adhered to self-care either flexibly or with strict adherence to the regimen received more social support from family and friends. Patients with more peer support from other patients with diabetes had worse blood-glucose levels. Patients receiving 'emotional and instrumental' support from their friends and family adhered better to self-care.

Author & year	Objectives	Participants	Design & Measures	Findings
Trief et al (2001)	Examination of the relationship between marital adjustment, blood-glucose control and psychosocial adaptation to diabetes	78 insulin treated adults with type 1 (57%) or type 2 diabetes 58% female Mean age: 45 years	Cross-sectional Dyadic Adjustment Scale MOS–SF36 Problem Areas in Diabetes Scale HbA1c	Marital satisfaction predictive of glyceamic control, although the effect just missed statistical significance (p=.056). Marital quality related to adaption to diabetes with regard to emotional distress.
Williams & Bond (2002)	The role of social support and self efficacy in adherence to treatment	94 patients with diabetes (84% type 2) Mean age: 62 years 77% female 82% married Mean disease duration: 9.7 years	Cross-sectional Diabetes Family-Behaviour Checklist Summary of Diabetes self-care scales	Social support associated with self-efficacy and positive diet-related family interactions. A mediation effect was found for self-efficacy with positive diet self-care support and positive exercise self-care support.

1.5. Summary of social support in diabetes

In general, the findings of the studies examining the role of social support in treatment adherence and control of diabetes demonstrate that higher levels of social support favour better management of the condition. More favourable indicators of the role of social support were evident in the prediction of self-management behaviours such as exercise, dietary and medication adherence. Indeed, the studies of Glasgow and Toobert (1988); Toljamo and Hentinen (2001) and Williams & Bond (2002) found that social support was predictive of adherent behaviour, whereas Lo (1999) and MacLean and Lo (1998) found that social support was predictive of intentions to adhere to self-management behaviours. However, with regard to blood-glucose control social support appears to serve different functions according to the gender of the patient. A surprising finding is that men were in poorer control when satisfied with the level of support they received whereas women were in better control (Heitzmann and Kaplan, 1984; Kaplan & Hartwell, 1987). In addition, patients receiving support from other patients with diabetes were also likely to exhibit poorer control (Toljamo and Hentinen, 2001) while Trief et al (2001) did not find a significant relationship between marital quality and HbA1c. Such mixed findings make it unclear how the social environment influences the control of diabetes measured through blood-glucose assays.

1.6. Discussion

This chapter examined selected literature examining the social context in the management of diabetes. The concept of 'social support' has been shown to be consistent in demonstrating positive relationships with the selected outcomes in diabetic patients. In particular, these favourable results were observed in relation to good self-management behaviours. The often inadequate and inconsistent conceptualisation of social support and the instruments used to measure the construct may in part, explain the equivocal results. It is also likely that the patients used in studies are at differing stages of disease progression or

THE ROLE OF SIGNIFICANT OTHERS IN THE HEALTH BEHAVIOURS OF PATIENTS WITH TYPE 2 DIABETES

Aidan Joseph Searle

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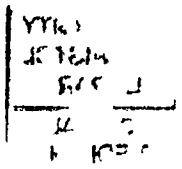

ABSTRACT

Previous research has demonstrated that the successful management of type 2 diabetes is dependent on the patients' social environment, in particular, the role of significant others. Therefore, the focus of this research was to explore the illness beliefs of patients with type 2 diabetes and their partners in a prospective study. The theoretical framework for the research was guided by the self-regulatory model of illness behaviour (Leventhal et al, 1984) which asserts that individuals conceptualise illness around 5 'core' dimensions regarding the *control, consequences, course, identity* and *cause* of their condition. These 'illness representations' describe the underlying differences on which individuals differ with regard to their illness.

In particular, the extent that patients and partners share representations of diabetes was explored in relation to the patients' adaptation and self-management of the condition. A total of 164 patient-partner dyads were recruited and followed-up at 12 months later. The illness representations of patients and their partners were assessed with diabetes-specific measures. Patients' self-management behaviours were assessed by self-report measures of adherence with diet, physical activity and medication at both time-points and objectively with a single measure of glucose control (HbA1c) at 12 months. In addition, marital satisfaction and psychological morbidity were assessed at both time-points. It was found that patient-partner dyads, generally, held similar representations of diabetes. In addition, logistic regression analyses demonstrated that partners' diabetes representations were influential in the extent of patients self-management behaviours, and levels of psychological morbidity after the influence of patients' representations, past behaviour, and demographic and clinical variables.

The findings are discussed in the context of previous research examining illness representations in chronic disease, the implications for the self-regulatory model of illness behaviour and future behavioural interventions to improve the self-management behaviours of patients with type 2 diabetes.

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The systematic review of the illness representations literature included in this thesis was made possible with assistance from Debbie Tallon (University of Bristol). Thanks are also due to the authors who provided their unpublished data for the review. Finally, this thesis would not have been possible without the participation of the patients with diabetes and their partners who kindly took part.

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Love and thanks to my family; Kate, Ines and Mara.

This thesis is dedicated to the memory of my father;

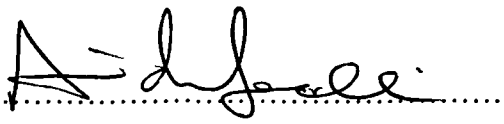
Francis George Searle (1914 - 2002).

AUTHOR'S DECLARATION

I declare that the work in this dissertation was carried out in accordance with the regulations of the University of Bristol. The work is original except where indicated by special reference in the text and no part of the dissertation has been submitted for any other degree.

Any views expressed in the dissertation are those of the author and in no way represent those of the University of Bristol.

The dissertation has not been presented to any other University for examination either in the United Kingdom or overseas.

SIGNED:.....  .....

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CHAPTER 1: THE SOCIAL CONTEXT AND THE MANAGEMENT OF DIABETES

1.1. Introduction

The present thesis aims to explore the role of significant others in the health behaviours of patients with type 2 diabetes. Before introducing the theoretical framework used to facilitate this enquiry, the extent and nature of how a diabetic patients' social environment impacts on disease management is examined. Therefore, this introductory chapter focuses on the importance of the social context in relation to patients' efforts to manage diabetes with regard to their health behaviours and control of blood glucose. In particular, the chapter will focus on the construct of social support and its relationship with adherence to treatment recommendations in patients with diabetes

A critique of social support and its measurement precedes the review of empirical studies examining the construct. There are also a number of points and issues regarding treatment adherence that are addressed before reviewing the empirical literature examining the role of social support and diabetes. These include; the prevalence and consequences of non-adherence in chronic disease, the distinction between intentional and non-intentional adherence, and the measurement of adherence. Finally, the ongoing debate regarding the terminology used to describe patients' fulfilment of treatment recommendations is also addressed.

What is type 2 diabetes?

Type 2 diabetes (non-insulin dependent) presents as a spectrum of metabolic abnormalities characterised by prominent insulin resistance and relative insulin deficiency. It accounts for about 90% of all cases of diabetes, tending to emerge in mid to late adulthood. The major risk factors for diabetes include a family history of diabetes, obesity (BMI > =27 kg per m ^{2}) age (> = 45 years),

hypertension, and high cholesterol levels. There is a progressive increase in the world-wide prevalence of type 2 diabetes. This increase is primarily the result of lifestyle changes, and in particular the steady rise in the prevalence of obesity (Amos et al, 1997, WHO, 1997). Finally, the prevalence of type 2 diabetes is projected to double by 2010 and is also accelerating in the younger population (*ibid*).

Consequences of type 2 diabetes

The longer the duration of diabetes the greater the likelihood of developing symptoms and signs of degenerative complications. The consequences of poor management of type 2 diabetes can be severe. Complications related to diabetes include blindness, amputations, and diseases of the kidneys, heart and central nervous system (Kaplan & Hartwell, 1987). The treatment of diabetes and its complications also constitutes a huge financial burden accounting for around 5% of the UK National Health Service budget (Leese, 1991).

Management of type 2 diabetes

Apart from being a serious chronic illness and social problem, the patient with type 2 diabetes has the principal responsibility for the management of their illness. In particular, the daily management of diabetes involves eating regular healthy meals, taking physical exercise, self-testing blood glucose levels and, for many patients, taking medicine. The goal of this combination of tasks is to maintain glucose levels within a target range - by achieving tight blood glucose control the rate of complications decreases (DCCT, 1993; UKPDS, 1998). Self-management not only involves completing such activities but considering the inter-relationships among these tasks and implementing appropriate changes in the daily plan when necessary. However, rates of non-adherence with these behaviours are high, ranging from 30–75% (Paes et al., 1998) and often result in poor disease outcomes Nicolucci et al., 1996). Indeed, Nicolucci et al speculate that the risk of diabetic complications could be reduced by up to one third, if

such 'avoidable' factors could be removed. Therefore, a major concern in the management of type 2 diabetes is how to encourage adherence with prescribed regimens.

The role of diet

Following a healthy diet is the primary treatment for type 2 diabetes. The goal of dietary intervention is to maintain near-normal glucose and lipid levels; maintain a reasonable body weight; prevent, delay or treat nutrition related risk factors and complications and improve overall health (Franz et al, 1994). However, dietary advice (along with physical exercise) is the most difficult aspect of the treatment regimen for patients to adhere with (Glasgow et al, 1997). An analysis of adherence to diet therapy among patients with diabetes showed that only 20-50% of patients followed dietary recommendations (Savage & Knowler, 1984; Skender et al., 1996). Moreover, Hixenbaugh and Winkley (2001) demonstrated that many patients have difficulty in eating the right type of food (59%), the right amount of food (49%) eating at regular intervals (36%) and maintaining an ideal weight (37%).

The current dietary recommendations for patients with type 2 diabetes are the same as for the general population. It is, therefore, the recommendation of Diabetes UK (formerly British Diabetic Association) to eat regular meals that are;

- low in fat (esp. saturated fat)
- high in fibre
- eat carbohydrates high in starch
- low in sugar

and to:

- eat five portions of fruit and vegetables a day
- reduce salt
- moderate alcohol consumption

In addition, patients are encouraged to achieve / maintain a desirable body mass index (BMI). All newly diagnosed patients with diabetes should receive dietary advice from a State Registered Dietitian and receive additional support from a trained member of their Primary Health Care Team (Avon Health Diabetic Care Manual, 1996).

1.2. Prevalence and consequences of non-adherence

Patient non-adherence with a treatment regimen may seriously undermine the effectiveness of medical care, and may, in turn give rise to poorer clinical outcomes (Haynes et al., 1996). Therefore, adherence with medical regimens is widely recognised as one of the principal challenges in healthcare. Non-adherence amongst patients is more prevalent when the illness is chronic and the treatment recommendations are largely prophylactic (Haynes et al., 1979; Meichenbaum & Turk, 1987). Approximations of the scale of the problem vary considerably, although average estimates of adherence in chronic illness converge at about 50% (Evans et al. 2001; Hulka et al. 1976; Wright, 1993).

A specific consequence of non-adherence is an increase in diagnostic and therapeutic procedures, with subsequent increased health-care expenditure. It has been speculated that the risk of diabetic complications could be reduced by up to one-third if adherence with health behaviours could be improved (Nicolucci et al, 1996). The far-reaching financial and human costs of non-adherence (Lowe et al, 1995) have led to many investigations to seek to identify the determinants of adherence. This work has identified a number of socio-demographic (e.g., age, gender, ethnicity, social class, disease status: Hawthorne et al, 1993; Koskinen et al, 1996; Nicolucci, et al., 1996; Dunbar-Jacob et al. 1995) and psychosocial correlates (e.g., social support, locus of control, health beliefs, psychological morbidity: Fukunishi et al, 1998; Schoenberg et al, 1998; Schwartz et al, 1991), and has led to the development of interventions designed to promote adherence (Epstein & Cluss, 1993, Lustman et al, 1998). However, results indicate that many of these interventions have failed to

generate significant improvements in adherence and treatment outcomes (Haynes et al., 1998). Thus, the understanding of the factors which may influence medication adherence remains inadequate.

It is also acknowledged that many other factors influence adherence to treatment regimens such as the perceived efficacy of the treatment, cost-benefits of adherent behaviour, complexity of the regimen, side effects of medication, psychological morbidity and socio-economic status which have been explored elsewhere in the literature. In addition, issues such as the quality of the practitioner-patient relationship, satisfaction with care, understanding of the condition may also impact on adherence as described in the seminal work of Ley (1982,1988).

Intentional and non-intentional adherence

It is suggested that non-adherence behaviours fall into two broad categories (Horne, 1997). First, 'unintentional' non-adherence occurs when the patients' intentions to take the medication are impeded by barriers such as forgetting, and inability to follow the treatment instructions because of poor understanding, memory or physical problems such as poor eyesight or impaired manual dexterity. Second, 'intentional' non-adherence is when an individual chooses not to follow some or all of prescribed treatment recommendations or when an individual has learned to manipulate or deviate from treatment recommendations that suits his or her lifestyle. Intentional non-adherence is sometimes referred to as "intelligent non-compliance" in acknowledgement of the fact that, from the patient's perspective, it may be viewed as the result of a rational decision. This chapter focuses on intentional or 'intelligent' non-adherence.

Measurement of adherence

Multiple methods of assessment are used in research examining adherence to treatment recommendations including self-report questionnaires and diaries, biological markers, and clinical outcomes. However, there are important issues regarding the measurement of adherence with treatment regimens. Each method reveals somewhat different information about the patient's behaviour with regard to their regimen as well as different reports of adherence. Therefore, the selection of a strategy to measure adherence requires careful attention to the limitations of each method and a well-specified definition of adherence. Indeed, there is a danger that self-report measures of adherence may permit patient over-reporting due to failure of memory or understanding or deliberate omission of the truth to bias findings. Taking medication adherence as an example, when validated against objective measures such as pill counts or biochemical methods, self-report is highly variable in terms of accuracy (Francis et al, 1969). This has been observed across a range of therapies for chronic conditions including medications for hypertension (Rudd et al., 1989) and RA medications (Dunbar-Jacob, 1993). In addition, studies that rely on clinical outcome measures (e.g., blood pressure, HbA1c) may also be unreliable as a patients' condition may improve or deteriorate for reasons unrelated to adherence such as stress (Surwit & Schneider, 1993).

The 'adherence' versus 'compliance 'debate

Finally, there is considerable debate regarding the most appropriate terminology to use when describing patients' fulfilment of recommended health behaviours. Indeed, terms such as 'adherence', 'compliance' and 'concordance' are often used interchangeably in the literature. Some investigators argue that differences between these terms extend beyond semantics. Indeed, Trostle, (1988) asserts that the term 'compliance' is an expression of practitioner's medical authority over patients who are expected to obey without question. Others, such as Eisenthal et al., (1979) argue that 'adherence' is a confirmation of the active, participative role of patients in the management of their care.

Adherence has been defined as.....*'the extent to which the patient's behaviour (in terms of taking medications, following diets or other life style changes) coincides with medical or health advice'* (Haynes, 1979). More recently, 'concordance' has emerged as a term to describe an agreement reached between a patient and a practitioner that respects the beliefs and wishes of the patient determining whether, when and how medicines are to be taken. Although reciprocal, this is an alliance in which health care professionals recognise the primacy of the patient's decisions about taking the recommended medications. While acknowledging such differences in terminology, the term 'adherence' is used in the present thesis and is intended to encompass the definition given by Haynes (1979).

1.3. Social support: An introduction

Much research effort has been invested in the purported beneficial effects of social support on health and well-being. Indeed, empirical evidence suggests that social support is associated with greater adherence with treatment regimens (Levy, 1986). Before examining this work two general models that explain how social support may impact on treatment adherence in chronic disease are introduced. First, the 'main effects' model of social support is considered to be a positive and useful resource such that the benefits are great even when people are not exposed to stressful situations such as chronic illness (Cohen & Syme, 1985). The second model known as the 'buffering' model, suggests that social support may serve as a source of protection (as a buffer) against adverse effects resulting from the presence of a stressor (Cohen & McKay, 1984). Indeed, it is likely that social support may enhance adherence, either directly (through encouragement, reassurance, reinforcement, systematic cues, bolstering of competence, and motivation) or indirectly (by buffering the effect of factors that may impede adherence, e.g., life stress, anxiety and depression). However, this section primarily addresses the literature examining the 'main effects' model of social support in studies with diabetes patients and the role of the spouse in particular. First, however, issues surrounding the measurement of social support are addressed.

Measurement of Social Support

The measurement of social support has been approached in two main ways. One approach conceives of social support in terms of the *structure* of an individual's interpersonal relationships or social network, the other in terms of the *functions* that these relationships or networks serve for an individual. The measurement of social support is based on tools assessing an individual's perception of either the availability of others who provide these functions or the actual receipt of these support functions (Stroebe & Stroebe, 1995). Therefore, 'structural' measures assess the existence or quantity of social relationships (i.e., availability of family and friends), whereas 'functional' measures of social support assess whether interpersonal relations serve particular functions (types of resources). Turner (1992) asserted that the effective measurement of perceived support provides the best lever by which to estimate the relative significance of potentially modifiable social factors for health and well-being. Furthermore, conceptions of available social support are both dispositional and cognitive, whereas conceptions of perceived support are situational and behavioural, involving interaction between individuals (Dunkel-Schetter et al. 1992).

With regard to 'functional' measures, it has been proposed that social support consists of multiple components. Indeed, Schaefer et al. (1981) studied the relationship between social network size and three types of social support; 1. 'tangible' (or 'instrumental'), 2. 'emotional' and 3. 'informational'. The three types of support were examined in relation to stressful life events, psychological symptoms, morale and physical health status, hence recommending the need to study these components separately. 'Instrumental' support consists of behaviours that directly help the person in need (i.e., practical help with work etc). 'Emotional' support involves providing empathy, care, love and trust. Finally, 'informational' support involves providing people with information that they can use in coping with their problems. However,

House and Kahn (1985) also include 'appraisal assistance' which is closely related to 'informational support'. It also involves the transmission of information relevant for an individual's self-evaluation. Finally, Cutrona (1990) added a fifth component, 'social integration', which combines *structural* and *functional* characteristics of support.

A problem with only measuring recipient perceptions of social support instead of the actual support that is given is that such perceptions are not always accurate. Such perceptions are not only based on what the recipient felt was needed versus what was actually given, but what the provider(s) perceived was needed by the recipient. In addition, provider and recipient perceptions do not correlate well. For example, providers may feel that they are giving more than what recipients feel they are receiving (Sarason et al., 1990). Recipients may also be dissatisfied and consider it negative support if the provider encourages behaviours that the recipient does not want to display (Tilden, 1985).

When evaluating social support it is also necessary to consider cause and effect. For example, it may be difficult to determine whether a lack of social support contributed to a problem occurring (e.g., depression) or if the problem was pre-existing in the individual and thus influenced the lack of adequate social support. Researchers have tended to ignore this phenomenon and assume that social support always results in positive outcomes. Also, researchers tend not to examine social support and changes in social network over extended periods of time (Kahn, 1994). Furthermore, support may vary throughout one's life, or even through the course of a stressful life event such as chronic illness. As a result it is difficult to evaluate this cause-effect phenomenon.

Support from significant others

A supportive family environment has been identified as a particularly important source of social support for chronically ill individuals (Moos & Moos, 1986). Furthermore, an early study demonstrated that support provided by the spouse may determine adherence to long-term medical regimens (Doherty et

al.,1983). The authors examined the influence of social support on adherence with hypertensive treatment from the perspective of the participant, the spouse and medical staff members. The authors reported that hypertensive men who had highly supportive spouses were more likely to adhere to their medication regimen than men with less supportive spouses. The health beliefs of the spouse were also related to levels of support provided. Indeed, wives who believed more strongly in the benefits of the therapeutic regimen were more likely to offer higher support to their husbands. This seminal study demonstrated the importance of spousal health beliefs, provision of support and the implications for adherent behaviour.

1.4. Social support and diabetes management

With regard to the topic of the thesis, studies examining the role of social support and marital satisfaction in the management and control of diabetes are reviewed in the following section. These studies are also summarised in Table 2.1.

A search was conducted to locate empirical studies examining the role of the social context in the management and control of diabetes. In particular, the search focused on finding literature examining the 'social support' in the context of treatment adherence in adult diabetic patients. Quantitative studies published in the English language were located through undertaking electronic database searches on 'PsychInfo', 'BIDS', 'Web of Science' and 'Medline'. Further literature was found by hand searching journals and reference lists from relevant journal articles.

Family support in type 2 diabetes

MacLean and Lo (1998) examined expected success in adherence with exercise and diet regimes in 95 patients with type 2 diabetes. The aim was to determine if family support was associated with adherence and intentions to continue to adhere. Family support was assessed with the Perceived Social Support from

Family Scale (Famsup: Procidano & Heller, 1983). The General Health Questionnaire (Goldberg, 1978) was used to assess transient and chronic stress. In addition, variables pertaining to intention, self-efficacy and self-esteem (Self-Esteem Inventory; Rosenberg, 1995) were also evaluated. The results from regression analyses demonstrated that adherence was a function of the capacity to utilise family support, positive attitudes, high self-esteem, absence of stress and acceptance of the challenges of the illness. The importance of good family support, absence of stress, and capacity to take up the challenges of the disease was replicated by Lo (1999) with regard to successful adherence in 146 diabetes patients dependent on insulin.

Overall, the findings of these studies indicate that patients with diabetes who have access to good social support and experience less stress are more likely to engage in adherent behaviours. However, as these were cross-sectional studies it is not permissible to make causal predictions, it is possible that good intentions to adhere attract higher levels of support from the patient's family. It is also reiterated that actual adherence was not measured, instead a measure of the patient's efficacy and intention to comply with the regimen was utilised. Furthermore, no distinction was made between diet, exercise and blood-glucose testing, therefore it cannot be assumed that patients' intend or are able to adhere equally to these management requirements. It is also uncertain to what extent such findings can be viewed as indicators of patients' actual behaviours regarding the successful management of diabetes. It is well documented from previous research that intentions to perform a health behaviour do not necessarily translate into an action been taken. Indeed, it may be that further cognitive activity is required to ensure that intentions are translated into actions (Norman & Conner, 1996).

In a study of 213 insulin-treated patients with diabetes Toljamo and Hentinen (2001) examined the role of social support and adherence to self-care regimens. Social support was assessed with an instrument developed for the study based on the definition of social support provided by House (1981). It consisted of 13

items relating to 'emotional', 'instrumental', 'informational' and 'peer' support from other patients. Adherence to aspects of the diabetic regimen were measured with a 20-item scale covering insulin treatment, diet, exercise and blood-glucose monitoring. Metabolic control was measured with levels of HbA1c taken from patient records. Measures of HbA1c reflects patients' mean metabolic control over the 6-12 weeks preceding measurement and is part of the routine management of patients with diabetes and widely accepted as reliable and valid index of metabolic control (Nathan et al., 1984).

Factor analysis of the adherence to self-care scale revealed two distinct factors: 'flexible self-care' and 'regimen adherent self-care'. These factors were then dichotomised at their median value to give the following four adherence categories: 1) 'regimen-adherent self-care', 2) 'no regimen-adherent self-care', 3) 'flexible self-care' and 4) 'no flexible self-care'. The factor structure of social support was also examined. The items regarding 'emotional' and 'instrumental' support loaded highly on the same factor, and were combined to form a single variable labelled 'emotional and instrumental' support. The remaining variables of 'informational', 'peer', 'negative' and 'financial' support remained intact. Logistic regression analyses were employed to determine predictors of neglect of self-care. Patients who adhered to self-care either flexibly or with strict adherence to the regimen received more social support from family and friends than those who neglected self-care. There were no statistically significant relationships between other types of social support and adherence to self-care. Surprisingly, those who perceived more peer support from other patients with diabetes had worse blood-glucose levels. Getting no 'emotional and instrumental' support was related to neglect of self-care. The authors concluded that adherence to self-care was associated with support from family and friends. In particular, those with 'emotional and instrumental' support from their friends and family adhered better to self-care.

For efficiency in the operationalisation of social support in this study, the type and source of support were combined. However, in so doing, some

information may have been lost; therefore social support may be best assessed with separate measures to capture more accurately the nature of support. A further limitation, is that participants were regular attenders at a diabetes clinic and thus must be considered as having a more responsible approach to managing their disease and may not be 'typical' diabetes patients.

Glasgow and Toobert (1988) prospectively, examined the influence of the social environment in relation to health outcomes in 127 patients with type 2 diabetes. The social environment was assessed with the Diabetes-Family Behaviour Checklist (DFBC), a self-report measure specifically developed to assess social support received from family members for the performance of self-care activities in patients with type 1 diabetes (Schafer et al., 1986). The scale was modified (DFBC-II) for use in a population with type 2 diabetes. Two versions of the DFBC-II were administered; one for the subject and another for the partner or 'significant other'. Four different aspects of the diabetes regimen were assessed (glucose testing, medication taking, diet and exercise). Dietary adherence was also measured with a 3-day food record and subjects were trained to estimate portion sizes and asked to weigh servings of meats and cheeses. Adherence to medication, physical activity, and glucose testing was assessed with a version of the Summary of Diabetes Self-Care Activities scale. It was demonstrated that measures of family support were the strongest and most consistent predictors of a composite measure of adherence in patients with type 2 diabetes. However, the results of this study are tempered by relying solely on self-reports of family interaction. In addition, the process of self-monitoring family interactions may have altered patterns of self-care over the period of study.

The role of social support and self-efficacy (belief in the ability to perform a given behaviour) in the self-care behaviours of 94 patients was assessed in patients with type 1 or type 2 diabetes (Williams & Bond, 2002). The ability to perform behaviours in four regimen areas; blood glucose testing, exercise, eating habits and medication were assessed with a 29-item questionnaire. The

frequency of both supportive and unsupportive family behaviours was assessed with the DFBC (Schafer et al, 1986). Items of the scale addressed blood-glucose testing, diet, exercise, medication, and general regimen adherence. Participants nominated their closest supporter (e.g., wife, husband, daughter) and indicated how often that person assisted in the performance of a given self-care behaviour. Response options ranged from 'never' to 'at least once a day'. Self-care behaviour was assessed with the Summary of Diabetes Self-Care activities scale (Toobert & Glasgow, 1984). The family member nominated as providing the most help with diabetes management was the spouse or partner (n=75, 83% of those with family support). It was demonstrated that self-efficacy was associated with social support and positive diet-related family interactions. In addition, a mediation effect was found for self-efficacy with positive diet self-care support and positive exercise self-care support. However, when the effects of self-efficacy were controlled, social support was no longer a significant independent predictor of self-care. The authors argue that the results support Bandura's (1977) claim that social support is a source of efficacy information but does not affect behaviour directly, thus social support could be an important source of efficacy information among diabetes patients. Although this study showed that the receipt of social support was a predictor of dietary and exercise behaviour, no such relationship was found for medication adherence. This may be a function of using a composite measure of regimen adherence such as the Summary of Diabetes Self-care Scale which may not have been able to differentiate among different aspects of behaviour. Alternatively, if this finding truly reflects the relationship between social support and medication adherence it affirms the view that 'it should not be assumed that because a family member is supportive of a patient's adherence to one aspect of the regimen.....that he or she will be supportive of other diabetes activities' (Glasgow & Toobert, 1988, p. 384)

Social support and gender

It has been observed that social support has differential effects for men and women in relation to health (Antonucci, 1985; Kessler et al., 1985). These effects

have also been demonstrated in type 2 diabetes. In a small and simple study (n= 37), Heitzmann & Kaplan (1984) examined the role of support in relation to blood-glucose control. The patients' social support network was measured by the Social Support Questionnaire (Sarason et al., 1983). The SSQ provides separate scores for *network* size and *satisfaction* with available support.

A single measure of HbA1c was used to assess the extent of control of diabetes The measurement of HbA1c provides a measure of blood glucose control such that higher levels indicate poorer control of diabetes. Groups of high and low recipients of social support were formed by median split and analysis of variance was conducted to determine the effects of gender and social support on levels of HbA1c. It was demonstrated that women were in better control of type 2 diabetes when they were more satisfied with their social support network. In contrast, men were in poorer control when they had high satisfaction with social support scores. However, the social support network scores were not significantly related to glucose control for men and women.

These results were replicated in a prospective study Kaplan and Hartwell (1987) using the Social Support Questionnaire (Sarason et al., 1983). Regimen adherence was assessed via levels of HbA1c. Male patients expressing greater satisfaction with perceived social support exhibited poorer glyceamic control at 18-months follow-up. In addition, women selected spouses as supports only half as often as men did. This study highlighted the complexity of the relationship between satisfaction with social support, network size and gender with the control of type 2 diabetes.

Together, these studies suggest that social support, network size and satisfaction have different functions for men and women with type 2 diabetes. One explanation is that social support serves as a more important buffer of stress for women than it does for men. According to the buffering hypotheses, social support should have greater effects under higher levels of stress. In this study women reported greater worry than men relating to their diabetes and, in

turn, may have a more positive response to high levels of social support. However, it is unclear why diabetes should be correlated with low worry for men but not for women. It is possible that men have a more casual disposition toward their illness and that they receive support for this stance. Alternatively, it could be that a satisfactory support system directly affects behaviours that result in good or poor control of diabetes. For example, networks found satisfactory to women may support behaviours that lead to good control. In contrast, networks satisfactory to men may reinforce lifestyle patterns that are not in the patients' best interests.

Social Support and family functioning

It has been proposed that the family system has a role in the initiation, selection of symptoms, clinical course, use of clinical facilities and adherence to medical treatment in chronic disease (Anderson & Auslander, 1980, Hansen & Hengeller, 1984). The 'family functioning' concept refers to a set of patterns or interactions among members of a family (Epstein et al., 1978). During the course of a chronic disease such as diabetes, adverse interactions may impose an excessive load on the capability for adaptation of the family. Thus, it is suggested that under such circumstances, family functioning may change to 'rigid' control, which may threaten family stability.

Garay-Sevilla et al (1995) examined the role of social support in adherence to diet and medication in patients with type 2 diabetes. Support was assessed in 200 patients with a modified diabetes-specific questionnaire (Ruggiero et al., 1990). Family functioning was evaluated with the modified McMaster model (Epstein et al., 1978). Adherence to treatment was assessed with a seven-item self-report measure concerning daily intake of food, acceptance and adherence to prescribed diet and the patient's interest in keeping an appropriate weight. In addition, medication adherence was assessed with three questions about continuity of intake (e.g., self decided changes of doses). Regression analyses demonstrated that adherence to diet was predicted positively by social support

and disease duration. Social support was also the main determinant of medication adherence. In addition, adherence to medication was lower in patients from families with *'rigid control'* (if permissions for members of the family were seldom given) than those with *'laissez-faire'* (if permissions were almost always granted) type of control or *'flexible'* control (if permissions were frequently obtained).

A rigid control of behaviour within a family may imply decreased adaptation to change, in particular to deleterious changes such as chronic disease in one of its members. In turn, this may favour denial of the disease. It may also enhance the development of conflict with the authority, increasing the denial of the disease resulting in a decrease in adherence. Finally, the results are compromised by a response rate of just 20%. Therefore it is possible that those consenting to participate were naturally more concerned about their condition and consequently exhibited greater adherence.

The marital relationship and blood-glucose control

Trief et al, (2001) examined the relationship between marital adjustment, blood-glucose control and psychosocial adaptation to diabetes. A mixed sample of 78 married patients aged 18-55 years with insulin-treated type 1 or type 2 diabetes (≤ 1year) participated in the study. Marital quality was measured with the DAS (Spanier, 1976). Functional health status was measured with the MOS-SF36 (Ware & Sherbourne, 1992). Diabetes-specific emotional distress was assessed with the Problem Areas in Diabetes Scale (PAID; Polonsky et al, 1995). Finally, glucose control was assessed with a single measure of HbA1c.

Higher levels of marital satisfaction predicted lower scores on the PAID. Marital quality did not predict levels of HbA1c when treated as a continous variable. Thus subjects were divided into three groups; good glyceamic control was defined as ≤ 7.4%, acceptable control was defined as a value between 7.5-8.4%, and poor glyceamic control was defined as HbA1c value of > 8.4%. These figures were based on the findings of the Diabetes Control and Complications Trial which demonstrated that the risk of significant microvascular

complications dramatically increases when HbA1c levels exceed 8.4% (DCCT Research Group, 1988). Due to small numbers 'acceptable' and 'poor controlled' patients were combined for analysis and dichotomised into two groups; HbA1c < 7.4 and ≥ 7.4%. Stepwise regression analyses demonstrated a trend for marital satisfaction measures with the DAS to be predictive of glyceamic control, although the effect just missed statistical significance (p=.056). The authors concluded that marital quality does relate to an individual's adaptation to diabetes with regard to levels of emotional distress. Although a significant relationship was not found for marital satisfaction and HbA1c it is suggested that the marital relationship may be more powerful than general family support in terms of its impact on glyceamic control. Finally, the cross-sectional design prohibits enquiry into causality as it cannot be determined if a poor relationship leads to poor illness adaptation and glucose control or that poor control/adaptation leads to a more problematic marital relationship. Finally, by including patients with both type 1 and type 2 diabetes it is difficult to delineate how support and marital satisfaction differ for these medically defined sub-groups. Indeed, regular insulin administration by patients with type 1 diabetes may pose unique challenges compared with type 2 diabetes patients that are primarily managed by diet.

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Table 1.1 . Summary of studies examining social support or spouse support in the management and control of diabetes.

Author & year	Objectives	Participants	Design & Measures	Findings
Heitzmann & Kaplan (1984)	To determine the relationship between social support, gender and glucose control	37 type 2 diabetes patients 51% Male Mean age: 53 years	Cross-sectional Social Support Questionnaire (Sarason et al, 1983) HbA1c	Women were in better control of type 2 diabetes when they were more satisfied with their social support network. Men were in poorer control when they had high satisfaction with social support scores
Kaplan & Hartwell (1987)	To determine the relationship between social support, gender and glucose control	77 patients with type 2 diabetes 73% female Mean disease duration: 17 years Mean HbA1c: Males= 8.3%, Females=8.9%	Prospective: (18 months follow-up) Social Support Questionnaire (Sarason et al, 1983) HbA1c	Male patients expressing greater satisfaction with perceived social support exhibited poorer glycemic control. In addition, women selected spouses as supports only half as often as men did
Glasgow& Toobert (1988)	To investigate the predictive validity of the social environment with regimen adherence	127 adults with type 2 diabetes 69% female Mean age: 61 years Mean disease duration: 9.1 years Mean HbA1c: 9.35%	Prospective (6 month follow-up) Diabetes Family-Behaviour Checklist Summary of Diabetes self-care scales HbA1c	Family support was the strongest and most consistient predictor of a composite measure of adherence in patients with type 2 diabetes

Author & year	Objectives	Participants	Design & Measures	Findings
Lo (1999)	To determine the role of family support and stress in adherence	146 patients with type 1 diabetes 56% female Age: 46-55 years	Cross-sectional General Health Questionnaire Perceived Social support from family scale	Expected success in adherence associated with good family support and the abscense of stress
MacLean & Lo (1998)	To determine the role of family support and stress in adherence	95 patients with type 2 diabetes Age 46-65 years 56% female	Cross-sectional General Health Questionnaire Rosenberg self-esteem inventory Perceived Social support from family scale	Intentions to adhere were a function of the capacity to utilise family support, positive attitudes, high self-esteem, absence of stress and acceptance of the challenges of the illness
Toljamo & Hentinen (2001)	To determine what type of social support influences adherence and glucose control	213 insulin treated diabetes patients Disease duration: > 1 year 58% Male Mean age: 40 years Mean HbA1c: 8.1%	Cross-sectional Social support scale developed for study measuring 'emotional', 'instrumental' , 'informational' 'financial' and 'peer' support 20-item Self-care scale developed for study measuring insulin treatment, diet, exercise, blood glucose monitoring and responsibility HbA1c	Patients who adhered to self-care either flexibly or with strict adherence to the regimen received more social support from family and friends. Patients with more peer support from other patients with diabetes had worse blood-glucose levels. Patients receiving 'emotional and instrumental' support from their friends and family adhered better to self-care.

Author & year	Objectives	Participants	Design & Measures	Findings
Trief et al (2001)	Examination of the relationship between marital adjustment, blood-glucose control and psychosocial adaptation to diabetes	78 insulin treated adults with type 1 (57%) or type 2 diabetes 58% female Mean age: 45 years	Cross-sectional Dyadic Adjustment Scale MOS–SF36 Problem Areas in Diabetes Scale HbA1c	Marital satisfaction predictive of glyceamic control, although the effect just missed statistical significance (p=.056). Marital quality related to adaption to diabetes with regard to emotional distress.
Williams & Bond (2002)	The role of social support and self efficacy in adherence to treatment	94 patients with diabetes (84% type 2) Mean age: 62 years 77% female 82% married Mean disease duration: 9.7 years	Cross-sectional Diabetes Family-Behaviour Checklist Summary of Diabetes self-care scales	Social support associated with self-efficacy and positive diet-related family interactions. A mediation effect was found for self-efficacy with positive diet self-care support and positive exercise self-care support.

1.5. Summary of social support in diabetes

In general, the findings of the studies examining the role of social support in treatment adherence and control of diabetes demonstrate that higher levels of social support favour better management of the condition. More favourable indicators of the role of social support were evident in the prediction of self-management behaviours such as exercise, dietary and medication adherence. Indeed, the studies of Glasgow and Toobert (1988); Toljamo and Hentinen (2001) and Williams & Bond (2002) found that social support was predictive of adherent behaviour, whereas Lo (1999) and MacLean and Lo (1998) found that social support was predictive of intentions to adhere to self-management behaviours. However, with regard to blood-glucose control social support appears to serve different functions according to the gender of the patient. A surprising finding is that men were in poorer control when satisfied with the level of support they received whereas women were in better control (Heitzmann and Kaplan, 1984; Kaplan & Hartwell, 1987). In addition, patients receiving support from other patients with diabetes were also likely to exhibit poorer control (Toljamo and Hentinen, 2001) while Trief et al (2001) did not find a significant relationship between marital quality and HbA1c. Such mixed findings make it unclear how the social environment influences the control of diabetes measured through blood-glucose assays.

1.6. Discussion

This chapter examined selected literature examining the social context in the management of diabetes. The concept of 'social support' has been shown to be consistent in demonstrating positive relationships with the selected outcomes in diabetic patients. In particular, these favourable results were observed in relation to good self-management behaviours. The often inadequate and inconsistent conceptualisation of social support and the instruments used to measure the construct may in part, explain the equivocal results. It is also likely that the patients used in studies are at differing stages of disease progression or

have differing levels of severity and this may in turn influence the provision and receipt of social support and study outcomes. For example, the experience of a disease such as diabetes may fluctuate with regard to symptoms, therefore, influencing levels of support from others. In turn, patients may be more (or less) motivated to adhere to treatment when experiencing acute symptoms. The employment of prospective designs that include assessments of symptomatology from the patient's perspective may permit the dynamic interaction with psychosocial variables to be delineated. With further regard to study design, the majority of the studies reviewed are cross-sectional in design.

The findings suggest that different effects of social support exist according to the provision of support and interaction with demographic and contextual factors. Indeed, the findings have reinforced the assertion that social support may not be beneficial for all individuals, and this appears to have particular relevance for males with diabetes. Also a distinction should be made between social support *per se* and support provided by the family, particularly the spouse. Indeed, some studies (Doherty et al. 1983, Garay-Sevilla et al. 1995) demonstrated an influence of the spouse in adherence to treatment in conditions such as hypertension and diabetes. In addition, the cross-sectional design of many studies prohibits causal inferences regarding social support and adherence. It may be that high adherers tend to attract more social support rather than low adherer's receiving less support. Again, there is a need for well-designed prospective studies to delineate this relationship. Also, the type of support received is clearly of importance. For example, Toljamo & Hentinen's (2001) study showed that a mix of 'emotional' and 'instrumental' support favoured better adherence and Garay-Sevilla et al (1995) showed that patients receiving social support in a *flexible* family environment exhibited better medication adherence.

The studies reviewed have included patients with both type 1 and type 2 diabetes which to some extent prohibits the generalisation of the findings. The management of type 1 diabetes is believed to more genetic in its aetiology than type 2 diabetes that is believed to have a stronger behavioural component

suggests that managing the disease may be a different experience for either group of patients. Indeed, type 1 diabetes is primarily managed with insulin whereas the management of type 2 diabetes requires a careful balance of diet, exercise and medication (and insulin in more chronic cases). Adherence to such regimens may not be associated with the same psychosocial issues. A further point relates to the homogenous nature of the study participants across the studies reviewed. The study populations were typically drawn from Caucasian, middle income communities thus limiting the generalisation of findings to the wider diabetic community.

To conclude, it is apparent that adherence is likely to be influenced in a complex manner that involves a combination of psychological and social factors and these may vary between a specific condition and treatment regimen. Furthermore, what may be a determinant of one aspect of the regimen may not necessarily be a determinant of another. For example, a diabetes patient may adhere to prescribed medication but not exercise or dietary recommendations. It is clear that past approaches are insufficient in predicting which individuals are at risk of non-adherence. Finally, to conclude, the diversity of studies examining diabetic patients' social environment demonstrates that the quality of interactions with 'significant others' particularly the spouse or partner serves to influence a range of health behaviours. The role of the spouse or partner of the diabetic patient is therefore worthy of further consideration in studies examining adherence with diabetic regimens.

CHAPTER 2 PART 1 - ILLNESS REPRESENTATIONS IN CHRONIC DISEASE: A SYSTEMATIC LITERATURE REVIEW

2.1. Introduction

In Chapter 1 it was shown that the influence of the patients' social environment is an important determinant in patients' management of type 2 diabetes. The purpose of the present chapter is to explore the appropriateness of the proposed theoretical framework for the thesis in predicting relevant outcomes in the process of living with chronic disease. Indeed, it is proposed that the employment of the self-regulatory model of illness behaviour (SRM; Leventhal et al, 1984) will assist in exploring the role of patients' health beliefs in chronic disease. Of particular pertinence to the examination of the role of significant others in the health behaviours of patients with type 2 diabetes, the health beliefs of partners of patients with chronic disease are considered.

The SRM has been the focus of considerable research activity within health psychology and has resulted in a growing body of empirical studies examining the predictive utility of the model in the context of chronic disease including diabetes. In response to the current interest in utilising the SRM, a systematic review of studies was conducted. This systematic review aggregates the results of published and unpublished empirical studies that have utilised the SRM in the context of adults with chronic disease. More specifically, the review focuses on the extent that individual components of the illness representations framework are associated with or predict clinical, behavioural and psychological outcomes. An overview of the dimensions of the illness representations framework and the different approaches employed in measuring illness representations in empirical studies precedes the review.

2.2. Self-regulatory model

The SRM posits that the patient is an active participant in the health care process (Weinman & Petrie, 1997). It is also argued that an individual experiencing illness may perceive a range of problems that are pertinent only to that individual, while others experiencing the same condition have their own unique experiences. In order to make sense of and respond to these problems, patients create their own 'models' or representations of their illness which then influence their coping and care seeking behaviour (Cameron et al, 1993). The process is regarded as self-regulatory because the three components of the model, interpretation, coping and appraisal have been shown to interrelate in order to maintain the status quo. Therefore, if an individual's normal state of health is disrupted by illness, or the threat of illness, the model proposes that they are motivated to regain the balance (Leventhal & Diefenbach, 1991; Leventhal et al, 1984).

It is postulated that these representations emerge as soon as patients experience initial symptoms or are given a disease label, and may change with disease progression, the emergence of further symptoms and responses to medical intervention (Weinman et al, 1996). Furthermore, it is argued that not only do illness representations give personal meaning to patients' symptoms and experience of illness, but act as a framework for guiding and evaluating coping efforts that are evoked to deal with the illness. Moreover, self-regulation theory predicts that illness representations will be directly related to coping and, via coping, to adaptive or maladaptive outcomes (Leventhal et al, 1984, Weinman et al, 1996). In this way, the self-regulation process is considered to be dynamic, as feedback from appraisals of coping efforts influence cognitive representations, emotional responses and future coping efforts (Leventhal et al, 1980, 1984).

Dimensions of Illness Representations

Leventhal and colleagues identified four common themes or 'dimensions' of how people think about their illness via extended open-ended interviews with

patients recently diagnosed with hypertension, cancer or diabetes (Leventhal et al, 1980; 1984, Meyer et al, 1985). It was posited that each patient has their own 'common sense' beliefs regarding the *identity* or label assigned to the illness and knowledge of the symptoms associated with it. The *time-line* dimension assesses the perceived course the illness takes; for example whether the patient believes the illness will be acute or chronic in its duration. The perceived *cause* of the illness assesses the extent that various possible causal factors are responsible for causing the illness in question. The *consequences* dimension assesses the extent that the illness impacts on an individual's life; for example, in terms of the way other people see them. Finally, Lau and Hartman (1983) proposed a fifth dimension - *cure* or *control,* arguing that patients' models may also incorporate beliefs about the controllability of the condition; the extent to which they perceive they will make a recovery or limit disease progression. These five dimensions are regarded as the basic components of illness representations, influencing how patients conceptualise and cope with their condition (Leventhal et al, 1980, 1984).

Assessment of Illness Representations

The original work of Leventhal and colleagues used in-depth, semi-structured interviews with hypertensive and cancer patients as a means of eliciting illness representations (Leventhal et al, 1984). The interviews focused on perceptions regarding the *identity, time-line, consequences* and *causes* of these conditions. However, it was not a time-efficient, economic or reliable method and resulted in a large variation in the quality and quantity of response. Later, an attempt was made by Turk (1986) to operationalise the 'common-sense' constructs described by Leventhal (1980) in a questionnaire. The Implicit Models of Illness Questionnaire (IMIQ, Schiaffino & Cea, 1995) as it is known has four dimensions. First, *curability* reflects a combination of items from the *cause, cure* and *time-line* components of Leventhal's model. *Personal responsibility* includes *causes, consequences* and *identity* components, and *symptom variability* captures the cyclical *time-line* notion of the illness representation framework. Finally,

serious consequences is consistent with the *consequences* component of the illness representation framework.

In response to growing interest in patients' representations of illness and how they may influence outcomes in chronic disease, the theoretically-based Illness Perception Questionnaire (IPQ) was developed to assess illness representations (Weinman et al, 1996). The IPQ is based on the five dimensions of illness representation: *identity, time-line, consequences, cure / control* and *cause* and studies utilising the IPQ have provided support for these dimensions and have also shown links between illness representations and a range of psychological outcomes including coping (Heijmans, 1999; 1998, Moss-Morris, 1996, Scharloo et al, 1998) and mood (Fortune et al, 2000, Murphy et al, 1999).

Recently the IPQ has undergone further development. The Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al, 2002) divides the *control* dimension into personal and treatment control and *time-line* consists of two distinct scales *acute/chronic* and *cyclical.* In addition two new scales have been included to measure *emotional representations* (emotional responses to illness) and the extent to which patients feel they understand their condition, namely *illness coherence.*

In parallel with the assessment of illness representations utilising the IPQ and the IPQ-R, patients' representations of chronic disease have been examined using the Personal Models of Illness framework (Hampson et al, 1990). Based on the SRM, Hampson and colleagues broadened the definition of illness representations to include patients' beliefs and emotions about the *cause, symptoms, course, treatment* and *consequences* of their disease and referred to these as 'personal models' of illness. However, in patients with diabetes (Hampson et al, 1990) and osteoarthritis (Hampson et al, 1994), a distinction between *course (time-line)* and *consequences* was not found thus a single internally consistent construct described as *seriousness* was formed.

Utility of illness representations

The introduction of the IPQ and IPQ-R led to a considerable increase in studies employing the SRM framework to investigate psychological correlates and determinants of outcome in chronic disease. Empirical studies with various methodological designs, across a range of chronic conditions, have demonstrated the consistency and validity of the five dimensions of patients' representations of illness (Baumann et al, 1989, Bishop et al, 1987, Lau & Hartman, 1983, Meyer et al, 1985). Moreover, illness representations have been shown to be related to the decision to seek health care (Baumann et al, 1989, Leventhal & Diefenbach, 1992, Cameron et al, 1993) and compliance with medical advice (Leventhal et al, 1980). More recently, illness representations have been examined in relation to patients' coping, adaptation and functioning in chronic disease (Heijmans, 1999; 1998, Moss-Morris et al, 1996, Scharloo et al, 1998). However, to date, there has only been one attempt to systematically review this growing body of literature. This meta-analytic review (Hagger & Orbell, 2003) demonstrated evidence to support the construct and discriminant validity of the *consequences, control/cure, identity* and *time-line* dimensions across a variety of conditions examined in 45 studies. Hagger utilised content analysis to classify coping and health outcomes into distinct categories and demonstrated theoretically predictable relations between illness cognitions and target outcomes. For example, *identity* was associated with the coping strategies of avoidance and emotional expression, *control* beliefs were associated with cognitive reappraissal, emotional expression and problem-focused strategies. Chronic *time-line* and serious *consequences* were associated with avoidance and emotional expression. With regard to health outcomes, perceptions of *control* were associated with psychological well-being, social functioning and vitality while *consequences, timeline* and *identity* were negatively associated with psychological well-being, role and social functioning and vitality

2.3. Aims and scope of the review

The present review was intended to broaden the scope of Hagger and Orbell's meta-analytic approach in several ways. First, the current review is systematic rather than meta-analytical in nature. This methodology was considered to be appropriate for two main reasons:

1. The self-regulatory framework has been adopted in studies that vary considerably in terms of the patient populations studied, their sample sizes, methods for assessing illness representations and also the selection and measurement of outcome measures. In the light of the heterogeneous nature of the data being synthesised, the present author considered that a systematic review method would be most appropriate in enabling a clear synthesis of such a diverse body of evidence.

2. Another important feature of meta-analytical approaches is that they examine the evidence for consistency. However, it may be inappropriate to expect consistency in the relationship between illness representations and outcomes across different diseases, as different illnesses place disparate demands on individuals. Thus, the predictive validity of the different dimensions should be expected to differ between patient groups. A systematic review method permitted the synthesis of evidence from disparate patient groups without having to expect such consistency.

The focus of this review is on the evidence pertaining to patients living with chronic conditions only. Chronic conditions were defined as long-standing illnesses (more than three months), which might be expected to have a profound impact on the lives of sufferers. Thus studies examining the illness representations of carers and partners were not included. The review included studies that have utilised any of the well-recognised scales measuring illness representations i.e., the illness perception questionnaire (IPQ; Weinman et al, 1996), the revised illness perception questionnaire (IPQ-R; Moss-Morris et al, 2002), the implicit models of illness questionnaire (IMIQ; Schiaffino & Cea, 1995) and the personal models of diabetes interview PMDI (Hampson et al, 1990, 1995). Studies that have operationalised any of the recognised dimensions

proposed by Leventhal et al. (1980;1984) through the use of non-validated scales were also included.

Finally, the categorisation of outcome measures differs from that of Hagger & Orbell. The present review examined the relationship between illness representations and three categories of outcome: clinical and psychological and behavioural. The clinical category encompasses both objective (e.g., blood pressure, blood glucose and cholesterol) and self-report measures (e.g., pain, disease severity) of the clinical status of the patient. The psychological category encompasses self-report measures of the patient's psychological responses to their condition (e.g., depression, adjustment, anxiety). Finally, the behavioural category assessed coping responses (coping strategies, treatment adherence, clinic visits). Researchers have examined the role of coping as a possible mediator but most have focused on coping scales. However, Leventhal originally conceptualised coping in terms of behaviours such as clinic attendance and medication adherence. Thus the present review will first examine the relationship between illness representations and outcomes (clinical and psychological) and will then go on to discuss evidence for the possible mediators of these outcomes, namely coping scales and coping behaviours. In contrast, Hagger & Orbell focused on two categories of outcome, namely coping and illness. Within coping they identified 7 groupings. However, all but one of these related to self-report measures of coping strategies. The only behavioural measure of coping considered was doctor visits. This contrasts with the present review in which the 'behavioural' outcomes category examines 6 behavioural measures of coping, in addition to self-report coping strategy measures. Similarly, within their illness outcomes category, Hagger & Orbell identified 6 groupings. However, psychological outcomes such as depression and anxiety were included within this category, whereas in the present review they were examined as separate outcomes.

In the description of findings more weight was given to studies deemed to be better designed and of higher quality (i.e., larger in sample size, prospective in design, and data analysed controlling for factors such as disease severity or illness duration). Studies which controlled for illness severity or duration were

deemed to be better as they consider the fact that illness representations are greater than the sum of the illness itself and may be more important in determining outcomes.

2.4. Method

The present review was conducted in accordance with recommended methods, the details of which are outlined below (Oxman, 1996; Cook et al, 1995).

Inclusion and exclusion criteria

To be included, studies had to report quantitative data on illness representations in adults with chronic disease and their associations with clinical, behavioural or psychosocial outcomes. Papers not including data on these relationships (e.g. theoretical papers), or which focused solely on illness representations of partners or carers of people with chronic disease, were excluded. However, this literature is addressed in detail in part 2 of this chapter.

Identification of papers and data extraction

Electronic searches were conducted using 'Web of Science' (1981-2002), 'Medline' (1966-2002) and 'PsychInfo' (1887-2002) using the following keywords: 'illness representations', 'illness perceptions', 'illness beliefs', 'self-regulation model', 'self-regulatory model'. Reference lists of all included studies were checked. Abstracts of recent health psychology conferences (British Psychological Society, European Health Psychology Society), and key journals (e.g. Psychology & Health, Journal of Health Psychology, Health Psychology) were searched by hand for relevant material. In addition, key authors in the field were also contacted to request further published or unpublished studies.

The author and an independent reviewer assessed the abstracts of retrieved articles and judged whether they met the inclusion criteria. Discrepancies were resolved through discussion. Articles that met these criteria were reviewed in full; data were extracted and recorded on standardized data extraction sheets (see Appendix 1). Information was collected on participants, design and measures, outcomes and significant results.

2.5. Results

Search results: Assessment of illness representations

A total of 57 studies were deemed to meet the inclusion criteria after review and discussion. The majority of the included papers were published recently; four (0.7%) were published between 1990-1994, 16 (27.6%) between 1995-1999, and the majority of studies 36 (62.1%) were published from 2000 onwards or remain unpublished to date. Of the included studies, 34 employed some or all dimensions of the original IPQ developed by Weinman et al, (1996). A further six studies employed the revised version of the scale i.e., the IPQ-R. The Personal Models of Illness Interview (Hampson et al, 1990) was employed in eight studies and one study utilised the Implicit Models of Illness Questionnaire (IMIQ; Schiaffino & Cea, 1995). A further eleven studies used other measures (e.g. non-validated measures derived from previous studies or qualitative work) based on the self-regulatory theory. Some studies employed more than one approach to measuring illness representations.

Study design

Forty-three of the fifty-eight studies (74%) adopted cross-sectional designs. Of the 14 studies adopting prospective designs, follow-up periods ranged from 2 to 12 months. The primary outcome of studies was often difficult to determine as most studies had multiple objectives and several outcome measures. Studies that reported associations between illness perception dimensions and clinical,

behavioural or psychological outcomes were included. Significant findings pertaining to illness representations and outcome variables relating to the stated aims of the review were extracted and tabulated.

Characteristics of participants

The patient groups represented in the reviewed literature represented a diverse range of disease groups including: diabetes (n=11), heart/circulatory disease (n=10), rheumatoid arthritis (n=7) chronic fatigue syndrome (n=4), inflammatory bowel disease (n=4), psoriasis (n=3), prostate cancer (n=3), Marfan syndrome (n=2), chronic obstructive pulmonary disease (n=2), epilepsy, MND, asthma, Huntington's disease, multiple sclerosis, HIV, osteoarthritis, schizophrenia and reflex sympathetic dystrophy (all n=1). A further study was undertaken in patients with various, mostly chronic conditions (e.g. psoriasis, RA, asthma) who were receiving homoeopathic treatment. Study sample sizes also varied ranging from 17 to 2056 participants and were all mixed gender except in three studies. Thirty-one studies (53%) included 100 participants or fewer and 27 (47%) studies included 101 participants or more.

2.6. Outcomes

The specific clinical, behavioural and psychological outcomes examined in this review are listed in Table 2.1. Such outcomes were chosen due their commonality in studies examining illness representations and outcomes in chronic disease.

Clinical outcomes

Clinical outcomes are defined as both objective and subjective measures that were presented as outcomes rather than measures of clinical severity, which have been controlled for in analyses of other outcome data. Some measures (e.g. the SF-20 and SF-36) are used as both outcomes and moderating disease

severity variables, but this section reviews only those studies that have used clinical measures as outcomes.

Table 2.1. Outcome variables examined in illness representation studies

Clinical	Psychological	Coping
Blood pressure	Depression	Coping scales
Blood glucose	Anxiety	Care-seeking (clinic attendance)
Cholesterol	Adjustment	Adherence to medication
Disability	Self-esteem	Adherence to dietary recommendations
Fatigue	Self-efficacy	Adherence to physical activity
Physical functioning	Worrying	Blood-glucose monitoring
Pain		
Illness severity		
Quality of life		

Objective clinical outcomes included blood glucose levels in diabetes, blood pressure, cholesterol and other clinical signs. Generic measures were used to measure pain, disability, physical functioning, fatigue and illness impact and severity. The most commonly used generic questionnaire was the Medical Outcomes Study Short-Form Health Survey (SF-20 and SF-36; Stewart et al, 1988). Subjective disease-specific measures included Psoriasis Disability Index (PDI; Finlay & Coles, 1995) Health Assessment Questionnaire (HAQ; Fries et al, 1980), Arthritis Impact Measurement Scale (AIMS; Meenan et al, 1984) and Daily Activities of Life (DAL; Schrier et al, 1990).

2.7. Objective clinical measures

Blood glucose levels in diabetes

Five studies reported data on illness representations and their relationship with measures of glycosylated haemoglobin (HbA1c; Hampson et al, 1990; 1995; 2000, Griva et al, 2000, Wearden et al, in submission). This clinical measure is commonly used to determine long-term glycaemic control, higher levels of HbA1c indicate higher blood glucose levels and hence poorer metabolic control.

First, in a small cross-sectional study of female patients with type 2 diabetes (n=46), it was demonstrated that personal model constructs failed to predict HbA1c levels after controlling for age and insulin status (Hampson et al, 1990). However, they did predict adherence to diet, exercise and glucose testing which are considered important in maintaining long-term glucose control in patients with diabetes. In another small cross-sectional study of young adults with type 1 diabetes (n=64) *consequences* and *identity* (and self-efficacy) accounted for 41% of the variance in HbA1c after controlling for age and disease duration (Griva et al, 2000). Finally, perceptions of *control* in recently-diagnosed patients treated with insulin were correlated with blood glucose control but not for long-standing non-insulin treated patients (Wearden et al, in submission).

In a prospective study with a larger mixed sample of patients with type 2 diabetes (n=78) personal model constructs prospectively explained 24% of the variance in HbA1c after controlling for demographic variables, disease duration and insulin status; lower levels of HbA1c were associated with believing that one's own behaviour *caused* diabetes, and that *treatment* was effective (Hampson et al, 1995). In another prospective randomised trial diabetic patients with stronger *control* beliefs had lower (better) glycosylated haemoglobin accounting for 29% of the variance after controlling for age, gender and comorbidity (Hampson et al, 2000).

Blood pressure

The relationship between illness representations and blood pressure in patients with hypertension was examined in one large cross-sectional study (Scisney-Matlock et al, 2001). The predictive utility of illness representations appeared to be age-related once other demographic factors were controlled. For those under 60 years of age, diastolic blood pressure was associated with fewer perceived *consequences* of hypertension, less *control* and a shorter *time-line.* For those over 60 years of age, increased perceptions of *control* were associated with increased diastolic blood pressure. These age differences may result from the notion that older adults act initially to self-manage symptoms of an acute, less serious nature but are quick to seek professional treatment when a health condition is perceived as serious or of long duration (Leventhal & Crouch, 1997). The expertise of older adults in dealing with the illness may be reflected in this situation in which older adults are more likely to seek and adhere to medical treatment, even in situations in which such adherence might not be associated with the same level of results for younger adults. They suggest that responses among the elderly are indicative of a heightened sensitivity to disease management issues, particularly the perceived control of hypertension.

It is also necessary to mention that this study did not use an established measure to assess illness representations but instead used the Cognitive Representations of Hypertension Scales developed specifically for the study. Although this measure comprised of items pertaining to the *identity, consequences, cause, control* and *time-line* sub-scales it did not resemble the sub-scales of the IPQ-IPQ-R, thus parity between these different scales cannot be determined.

Cholesterol

Two studies assessed the relationship between illness representations and cholesterol and both demonstrated significant but different relationships. First, in a large cross-sectional study Low Density Lipoprotein (LDL) cholesterol control (i.e. patients' ability to reach LDL treatment goals) was associated with

consequences, symptoms, and *timeline* beliefs of patients with hypercholesterolaemia (Brewer et al, 2002). Specifically, participants had less LDL cholesterol control when they believed that high cholesterol caused symptoms such as fatigue and tiredness, and better control when they believed that high cholesterol increased their risk of heart attack and stroke, and that their own cholesterol levels were stable over time.

The second study benefited from a prospective design and assessed LDL cholesterol levels in patients with diabetes: stronger beliefs in *treatment effectiveness* predicted lower serum cholesterol levels three months later after controlling for age, gender and co-morbidity (Hampson et al, 2000).

In summary, while most studies demonstrated associations between illness representations and clinical outcomes, there was little consistency between studies in terms of which representations were the most predictive.

2.8. Subjective measures of disability and quality of life

Medical Outcomes Study Short-Form Health Survey (SF-20 and SF-36)

Fifteen studies employed a measure of physical functioning, physical impact, functional activity/status or adaptive outcome. The most commonly used measure was the Medical Outcomes Study Short-Form Health Survey (SF-20 and SF-36). This instrument assesses patient functioning and well-being along several dimensions: physical, role and social functioning, general health perceptions, bodily pain, mental health and vitality. These scales were used in eleven of the included studies using both cross-sectional and prospective designs in patients with osteoarthritis (OA), diabetes, chronic fatigue syndrome (CFS), Addison's disease, Huntington's disease, reflex sympathetic dystrophy, psoriasis, chronic obstructive pulmonary disease (COPD), rheumatoid arthritis (RA) and prostate cancer.

Many of these studies report significant correlations between illness representations and outcomes on the SF-20 and SF-36. However, in the six cross- sectional studies which used regression analyses to control for demographic and clinical factors such as age, gender, disease duration and severity, fewer illness representations continued to be associated with SF-20 and SF-36 outcomes (Gonzalez, 2002a; 2002b, Heijmans, 1998, Helder et al, 2002a; Scharloo et al, 1998; Hampson et al, 1994). In the studies which used the IPQ or IPQ-R, perceived symptoms (*identity*) consistently explained variance in the outcome measures. In all cases, poorer outcomes on the SF-20 and SF-36 were associated with stronger illness *identity* (e.g. more symptoms) associated with the particular illness. However, there was inconsistency with regard to which dimensions were predicted by *identity*. For example, in Huntington's Disease, variance in pain, vitality, physical functioning, mental health and general health was explained by *identity* (Helder et al, 2002a). Whereas in COPD, role and social functioning, and general health perceptions were associated with *identity* (Scharloo et al, 1998). Of all the SF-20 and SF-36 dimensions, physical and social functioning were most likely to be associated with *identity* (as found in five and seven regression analyses respectively), and pain was least likely to be associated with *identity* (found in one analysis). Other IPQ dimensions were less likely to be associated with SF-20 and SF-36 outcomes: *consequences* was associated in four regression analyses, and *control, cause, emotional representations* and *timeline* were each associated with outcomes in one analysis.

The personal models framework also showed expected relationships between outcomes and illness constructs. For OA patients, better role functioning and overall perceived health correlated with fewer *symptoms* and believing that OA was less *serious* (Hampson et al, 1994).

There were three prospective studies examining illness representations and outcomes assessed by the SF-20 and SF-36 (Scharloo et al, 2000a; 2002b and Hampson et al, 2000). First, in (n=69) psoriasis patients, regression analyses

demonstrated that *identity* scores were negative predictors of physical and social functioning and health perceptions, and were positive predictors of depression and mental health at one year (Scharloo et al, 2000a). Perceptions of *identity* were also significant predictors in patients with COPD (Scharloo et al, 2000b), *identity* scores negatively predicted social functioning and health perceptions at one year. Finally, in a mixed sample of patients with type 1 and type 2 diabetes the personal model construct of perceived *seriousness* was predictive of physical functioning and *treatment effectiveness* predicted health perceptions. Whereas stronger beliefs in *seriousness* was a negative predictor of mental health. These results from the personal models framework appear to be inconsistent with the cross-sectional data reported by Hampson et al (1994) from work with osteoarthritis patients which questions the value of cross-sectional analyses.

Sickness Impact Profile (Disability)

The sickness impact profile (SIP; Bergner et al, 1981) is a measure of sickness-related dysfunction (disability). Dimensions of this scale can be grouped into physical dysfunction (ambulation, mobility and bodycare), social dysfunction (social interaction, alertness, communication), and role dysfunction (work, home management and recreation). In two cross-sectional studies employing the SIP the impact of sickness was associated with illness representations. For example, in a large cross-sectional study which conducted regression analyses, illness representations accounted for 37% of the variance in SIP dysfunction in CFS patients (*identity* and *consequences)* (Moss-Morris et al, 1996). In another large cross-sectional study of MS patients illness representations explained 32% of the variance in psychosocial dysfunction (*identity, illness coherence, consequences* and psychological *cause*), 17% of the variance in role functioning (*consequences*) and 11% of the variance in physical dysfunction (*identity, consequences* and *time-line*) (Jopson & Moss-Morris, 2003).

In the only prospective study, myocardial infarction (MI) patients' total score on the SIP was correlated with concurrent measures of *identity*, *timeline* and *consequences* (Weinman et al, 1996). Overall, the findings show that illness representations are predictive of illness-related dysfunction, however, there was little consistency in terms of which individual components were independent predictors but this may be an artefact of inherent differences between a 'functional' non-organic disease such as CFS and a disease with a known aetiology and course such as MS. It was also difficult to assess predictive consistency of individual components of the IPQ as the MS study reports regression for individual SIP variables while the CFS study reports regression for SIP total dysfunction.

Fatigue

The Fatigue Severity Scale (Chalder et al, 1993) was used to measure mental and physical fatigue in patients with MS (Jopson & Moss-Morris, 2003) and CFS (Edwards et al, 2001). Fatigue was independently associated with a strong illness *identity* in both studies, and by strong *consequences* in CFS and *control* beliefs in MS.

Disease specific measures of disability

Several studies assessed the relationship of illness representations with scores on disease-specific measures of disability. These scales included: the Psoriasis Disability Index (PDI; Finlay et al, 1990, Finlay & Kelly, 1987) which assesses psoriasis-related disruption to lifestyle; Daily Activities of Life (DAL; Kaptein et al, 1993; Schrier et al, 1990) used to assess ability to perform physical tasks in COPD patients; the Health Assessment Questionnaire (HAQ: Fries et al 1980) which assesses activities of daily living (e.g. hygiene, walking) in RA; and the Arthritis Impact Measurement Scale (AIMS; Meenan et al, 1984) which assesses physical functioning, depression, anxiety, pain, social functioning, general health perceptions and health status in patients with arthritis.

Illness representations significantly explained variance in all of these disease-specific measures with *identity* and *consequences* being associated the most with these outcomes. For example, in cross-sectional studies *identity* beliefs explained additional variance in functioning, over and above that explained by disease duration and medical variables in patients with COPD (Scharloo et al, 1998), RA (Tomlinson, 2001) and psoriasis (Scharloo et al, 1998) as did *control* beliefs in RA patients (Scharloo et al, 1998) and *consequences* in psoriasis patients (Scharloo et al, 1998, Fortune et al, 2002).

In a further cross-sectional study, patients with RA reporting more pain held stronger beliefs in the *consequences* of living with the condition (Tomlinson, 2001).
In patients with OA it was found that prior to joint surgery, functional activity was associated with patients' perceptions of the *consequences* of their illness (poorer functional activity was associated with more reported *consequences*). However, after patients had undergone surgery on the affected joint, functional activity was better in those who believed they had more *control* over their condition, and that it was not due to ageing (Orbell et al, 1998).

In the only prospective study utilising the HAQ, *identity* beliefs explained 20% of the variance levels in pain at 12 months while *identity* and perceived *consequences* explained 53% of the variance in tiredness after controlling for disease duration, and levels of pain and tiredness at baseline (Scharloo et al, 1999).

In summary, in these four studies of COPD, psoriasis, RA and OA, *identity* and/or *consequences* appear to be the most important predictors of functioning and disability. In RA and OA, *control* beliefs also play an important role.

2.9. Coping

Leventhal et al. (1984) suggested that not only do illness representations give personal meaning to patients' symptoms and experience of illness, but act as a framework for guiding and evaluating their coping efforts in dealing with the illness. Moreover, self-regulation theory posits that illness representations will be directly related to coping and, via coping, to adaptive or maladaptive outcome (Leventhal et al, 1984). Thus the illness representation framework has been applied in a number of studies examining coping strategies in chronic illness. In addition, health behaviours such as clinic attendance and adherence to treatment regimens may be viewed as objective indicators of coping behaviour therefore studies examining these outcomes are reviewed with the literature concerned with coping.

Coping strategies

The notion that illness representations have a 'direct' relationship with coping and adaptive outcome is not unequivocal. There is a body of evidence which suggests that adaptive outcomes in chronic disease are not mediated by coping (Scharloo et al, 1998, Heijmans, 1999, Moss-Morris et al, 1996 & Lawson et al, 2004). Indeed, some studies have found illness representations to be better predictors of adaptive outcomes than measures of coping (Earll et al, 1993, Heijmans, 1998, Watters, 2001, Wilby & Stewart, unpublished). However, as the focus of this review is to consider the utility of illness representations in predicting outcome in chronic disease the following sections examine studies that have employed coping as an outcome, rather than to test the mediating relationship between illness representations, coping and adaptive outcomes. The most frequently used coping measures were the COPE (Carver et al, 1989) and the Utrecht Coping List (Schreurs et al, 1993).

COPE

The COPE questionnaire assesses 15 different coping mechanisms, of which 10 can theoretically be divided into two categories: Emotion-focused coping

strategies are designed to regulate the emotional responses to the stressor and include seeking social support, engaging in positive reinterpretation and growth, acceptance, turning to religion and denial. In contrast, problem-focused strategies directed at altering the stressor in some way and include active coping, planning, suppression of competing activities, restraint and seeking social support for instrumental reasons. The remaining scales include mental and emotional disengagement strategies.

Five studies utilised components of the COPE as outcome measures of coping strategies. These studies assessed the associations between illness representations and coping in patients with IBS (Rutter, 2001, Rutter & Rutter, 2002), CFS (Moss-Morris et al, 1996), Huntington's disease (Helder et al, 2002a), and stroke (Wilby & Stewart, unpublished).

A large cross-sectional study of predominantly female patients with CFS employed twelve of the sub-scales most relevant to chronically ill patients (Moss-Morris et al, 1996). Illness representations significantly correlated with 8 of the 12 coping strategies assessed. Problem-focused coping strategies were most frequently predicted by *control/cure* and/or *consequences*; emotion-focused strategies by consequences, and disengagement strategies were predicted by all five IPQ dimensions.

The work of Rutter (2001) and Rutter & Rutter (2002) demonstrated that illness representations correlated with 9 of the 15 COPE sub-scales in patients with IBS. The IPQ dimensions *control/cure, consequences* and psychological cause of IBS were the most predictive. Problem-focused strategies were associated with *control/cure* and emotion-focused strategies with *consequences*. Path analysis revealed that coping variables also mediated the link between illness representations and the four main outcomes: quality of life, satisfaction, anxiety and depression. For example, acceptance coping mediated the link between *consequences* and quality of life, and behavioural disengagement mediated the link between *cure/control* and depression. However, there was no clear pattern as to which IPQ dimensions correlated with which COPE sub-scales.

Helder et al. (2002a) reported that only 3 of the 15 COPE sub-scales correlated with illness representations in a cross-sectional study of patients with Huntington's disease). Seeking emotional support and positive reinterpretation were associated with *cure* and *control* respectively, and mental disengagement correlated with *identity, time-line* and *cure.* No problem-focused strategies were predicted by IPQ dimensions. Finally, in a small cross-sectional study of younger stroke survivors IPQ constructs correlated with 4 of 14 COPE sub-scales. The *control/cure* dimension was the most predictive construct, correlating positively with positive reinterpretation, seeking social support and behavioural disengagement (Wilby & Stewart, unpublished).

Utrecht Coping List

Another widely used scale in the illness representations literature to assess coping is the Utrecht Coping List (UCL; Schreurs et al, 1993), a generic coping measure with well-documented reliability and validity (Schaufeli & Dierendonck, 1992 Hopman-Rock et al, 1997). The UCL consists of 49 items representing seven sub-scales: seeking distraction, expressing emotions, seeking social support, behavioural-avoidant, fostering reassuring thoughts, passive coping and problem-focused coping. Six studies employed the UCL, but it was utilised as an outcome measure in only two (Heijmans,1998; 1999),the remaining studies were concerned with the relative contribution of coping style in functioning and adaptation in chronic disease (Scharloo et al, 1998; 1999; 2000a; 2000b).

Heijmans used five of the seven UCL sub-scales in cross-sectional studies of patients with CFS (Heijmans, 1998) and in Addison's disease (Heijmans, 1999). There was some consistency between the two studies. In CFS patients, all five UCL sub-scales correlated with IPQ constructs. The *time-line* and *identity* dimensions were most likely to predict coping; higher scores on these IPQ constructs tended to correlate with more avoidance, and less adaptive (e.g. seeking social support, venting emotions) coping. In Addison's disease, the IPQ correlated with fewer (3 of 5) UCL sub-scales: behavioural- and cognitive-

avoidant, and emotion venting. Again, *time-line* and *identity* were most predictive; a stronger *time-line* was associated with more avoidance, and *identity* was associated with more avoidance and more adaptive (emotion venting) coping.

Other coping measures

The revised ways of coping checklist (WCCI-R; Vitaliano et al, 1985) was employed in a cross-sectional study of patients with epilepsy (Kemp et al, 1999). Illness representations correlated with all 4 coping sub-scales; *identity* (defined by symptoms) was associated with wishful thinking and avoidance whereas *identity* (defined by disease label) was negatively associated with avoidance and positively associated with seeking social support. The appraisal and coping questionnaire (ACQ; Anderson & Ekdahl, 1992) was used in a large cross-sectional study of patients with Reflex Sympathetic Dystrophy (Hendriks et al, 2000). It was demonstrated that emotion-focused coping correlated with more symptoms (*identity),* a stronger *time-line* and perceived *consequences* whereas problem-focused coping correlated with fewer symptoms (*identity)* and less perceived *consequences.*

Summary

In summary, studies reporting the relationship between illness representations and coping as an outcome variable relied mostly on correlations between beliefs and multiple coping sub-scales. Furthermore, all the studies utilising coping as an outcome have relied on cross-sectional designs which makes it difficult for meaningful interpretation of the findings. Nonetheless, illness representations were most predictive of COPE scores in CFS and IBS, and less so in Huntington's disease and stroke patients. The dimensions *control/cure* and *consequences* were most likely to be positively associated with emotion-focused and problem-focused coping strategies. In contrast, studies using the UCL found *timeline* to be the most positive predictor of avoidance coping in CFS and

Addison's disease whereas *identity* was negative predictor of adaptive coping in CFS and a positive predictor of adaptive coping in Addison's disease. The *identity* dimension was the only consistent predictor in studies using the WCCI-R. Studies often showed that emotion-focused and problem-focused coping strategies were predicted by different beliefs (usually *cure/control* and *consequences*), but there was little consistency between studies. For example, emotion-focused coping was associated with *consequences* in functional disorders such as CFS and IBS, but by *control/cure* in Huntington's disease and stroke. Across the three main coping strategies *causal* attributions were the least consistently associated dimension of illness representation with coping outcomes.

2.10. Behavioural outcomes

It has been posited that illness representations are related to the decision to seek health care (Baumann et al, 1989, Leventhal & Diefenbach, 1992, Cameron et al, 1993, Leventhal et al, 1980) and adherence with medical advice, consequently this issue is addressed in many studies in the illness representations literature. It is also argued that responses to health threats such as care-seeking and adherence to treatment regimens can also be interpreted as coping strategies; and are thus
considered as behavioural outcomes.

Clinic attendance

With regard to seeking health care; clinic attendance and hospital visits was examined in one cross-sectional study in patients with diabetes (Lawson et al, 2004). In this small study (n= 42) patients with type 1 diabetes the *treatment*

effectiveness dimension from the PMDI and *control* from the IPQ was associated with clinic attendance (Lawson et al, in press).

There were, however, three prospective studies which included clinic attendance as an outcome. In patients with psoriasis, only *control* and *identity* were significant predictors in psoriasis explaining 21% of the variance after controlling for previous visits at baseline, disease duration and severity (Scharloo et al, 2000a). In RA, visits were prospectively predicted by *consequences* of the condition after controlling for visits preceding study entry, disease duration and severity (Scharloo et al, 1999). In patients with COPD clinic visits were less likely if the *cause* of their condition was thought to be related to stress and other people (Scharloo et al, 2000b). In patients with OA *identity* was correlated with doctor visits (Hampson et al, 1994).

In summary, there was considerable evidence to suggest that illness representations are associated with clinic and hospital attendance. However, there was little consistency in terms of which representations were associated with this outcome.

Cardiac rehabilitation

Three studies utilising dimensions the IPQ to predict attendance at cardiac rehabilitation yielded contrasting results. First, in a cross-sectional study *identity* was the only significant predictor such that those with fewer perceived symptoms were less likely to attend (Whitmarsh et al, 2003).

There were two prospective studies including attendance at cardiac rehabilitation as an outcome. First, visits to the doctor three months post MI were positively correlated with *identity* and *consequences* (Weinman et al, 1996). Whereas, attendance at rehabilitation clinics at six months post MI was positively predicted by *control* and lifestyle *cause* beliefs after controlling for age and knowledge of cholesterol concentrations (Cooper et al, 1999). One

explanation for these inconsistent results may be due to the time-point at which illness representations were measured - perceptions of MI may change after a period of adjustment to the acute experience of a MI. This may be particularly pertinent if the patient has been attending rehabilitation clinics as the educative nature of rehabilitation may alter a patients' appraisal of the condition and subsequent representations of the condition.

Adherence to treatment recommendations

Self-reported adherence to prescribed medication was measured in cross-sectional studies of patients with hypercholesterolaemia (Brewer et al, 2002), hypertension (Cartwright & Lamb, unpublished), asthma (Horne & Weinman, 2002), haemophilia (Llewellyn et al, 2003), chronic fatigue syndrome (Pope & Woodcock, 2001), and acceptance of recommended treatment was examined in patients with HIV (Horne et al, 2000). Diabetes was the only condition for which several studies of treatment adherence existed hence these studies are discussed separately.

Medication

Of the non-diabetes studies, three cross-sectional studies reported *consequences* as a significant predictor of medication adherence. Those who perceived more *consequences* of their illness were more adherent to taking cholesterol lowering medication where demographic and clinical variables were used as co-variates (Brewer et al, 2002). In a small sample of patients with haemophilia (n= 33) adherence to clotting agents correlated with greater *consequences* and weaker identity beliefs (Llewellyn et al, 2003). In addition, analysis of variance demonstrated that patients under-treating with clotting agents perceived less perceived *consequences*. Adherence with preventive asthma medication was negatively predicted by *consequences* (Horne & Weinman, 2002) explaining 13% of the variance after controlling for demographic, clinical factors and treatment beliefs. Thus, surprisingly those perceiving greater *consequences* were less likely to adhere to medication, the authors suggest that due to the cross-sectional

design of the study, scores on this dimension may be a result rather than a determinant of adherent behaviour.

In a small study (n=35) of patients with HIV acceptance of antiretroviral agents was associated with a strong illness *identity*, and greater *time-line* perceptions (Horne et al, 2000). In a large cross-sectional study regression analyses controlling for age and the benefits and costs of treatment revealed no significant correlations between illness representations of patients with hypertension and adherence with medication (Cartwright & Lamb, unpublished). In another study of patients with CFS assessing *causal* attributions only, there were no associations with adherence to antidepressants (Pope & Woodcock, 2001).

There was only one prospective study examining medication adherence, a unique examination of patients consulting homoeopathic practitioners with various chronic illnesses. Adherence to homoeopathic remedies at 2 months was associated with *consequences* and *cause* beliefs (pollution and poor past care) after controlling for demographic factors (Searle & Murphy, 2000). In addition, non-adherence defined by the use of non-homoeopathic remedies was predicted by *identity* and *cause* beliefs (chance, own behaviour and other people). However, these results are tempered by a small sample size (n=30) and a short follow-up period of only two months.

Physical activity

Adherence to recommended exercise programs yielded contrasting results in two cross-sectional studies. In patients with Marfan Syndrome (an autosomal dominant condition of abnormal connective tissue) perceived *consequences* were positively correlated with exercise modification based on their diagnosis (Peters et al, 2001b). In a study of two patient groups (hypertension and diabetes) perceived *consequences* was negatively correlated with exercise in diabetes

patients only and failed to reach significance in regression analyses after controlling for age and costs and benefits of engaging in exercise

Diet

None of the IPQ dimensions were predictive in a cross-sectional study of hypertensive patients controlling for age and the costs and benefits of dietary adherence (Cartwright & Lamb, unpublished).
In a prospective study, attributions of *cause* 'poor past care' and 'chance' were positive predictors of dietary recommendations in homoeopathic patients with various chronic illnesses (Searle & Murphy, 2000).

Summary

The studies examining the relationship between illness representations and behavioural outcomes such as clinic attendance and cardiac rehabilitation have not provided consistent results and are hampered by a reliance on cross-sectional data. With regard to adherence with health behaviours it appears that the *consequences* dimension was most consistently associated with medication (Brewer et al. 2002, Llewellyn et al. 2003, Horne and Weinman, 2002) and exercise (Peters et al, 2001a).

2.11. Self-management of diabetes

Pertinent to the focus of this thesis, seven studies measured at least one of the mainstays of diabetes treatment i.e., blood-glucose testing, diet, physical activity, insulin and medication adherence. Of these, four studies utilised variations of the Summary of Diabetes Self-Care Activities scale (SDSCA) (Hampson et al, 1995; Glasgow et al, 1997; Skinner et al, 2002), all adopted cross-sectional designs except Hampson et al (1995). The SDSCA is a self-report measure of the frequency of adherence to different regimen activities (e.g.,

blood glucose testing, diet, physical activity and medication) in the preceding seven days and provides a global measure of level of diabetes self-care. Self-care assessed by the SDSCA correlates significantly with other more objective methods of assessment (Toobert & Glasgow, 1994, Glasgow et al, 1995). These studies all employed the PMDI to elicit illness representations.

Blood-glucose monitoring

Blood-glucose monitoring was assessed in four cross-sectional studies (Hampson et al, 1990, Griva et al, 2000, Glasgow et al, 1997, Skinner et al, 2002) and was positively associated with illness representations in both type 1 and type 2 patients. In three of these studies (Hampson et al, 1990, Glasgow et al, 1997, Skinner et al, 2002) glucose testing was associated with PMDI constructs however, these constructs were defined and assessed differently making the results difficult to compare. Overall, patients' beliefs regarding the *importance* or *effectiveness* of self-care activities such as glucose monitoring and glycaemic control, and *seriousness/threat* (e.g. consequences of diabetes on health and lifestyle) were the most significant predictors of glucose monitoring. For example, in Skinner et al's (2002) study of 358 type 1 patients, monitoring correlated with *treatment effectiveness* (e.g. importance of glucose monitoring to control and prevent complications). Furthermore, structural equation modelling demonstrated that *perceived threat* (which was derived from IPQ *consequences* and PMDI items, e.g. my diabetes is a serious threat to my current/future health) was a predictor of monitoring (Skinner et al, 2002). In Hampson et al's (1990) study of only 46 female patients with type 2 patients, monitoring was predicted by *treatment* importance (e.g. perceived importance of self-care activities such as glucose monitoring) after controlling for age and insulin administration. In a much larger study of 2056 type 1 and 2 patients of mixed gender, *treatment effectiveness/importance* and perceived *seriousness* were significant and explained 13% of the variance after correcting for insulin administration, age and education (Glasgow et al, 1997). Finally, monitoring also correlated with the IPQ construct *control,* and *self-efficacy* beliefs in type 1 diabetes (Griva et al, 2000). This study also showed that 39% of the variance in

total adherence (to glucose monitoring, insulin, diet, and exercise) could be explained by patients' *control* beliefs assessed with the IPQ.

Physical activity

Physical activity was assessed in five cross-sectional studies of patients with diabetes. Of these, three studies showed that exercise could be predicted by illness representations even after controlling for patient characteristics such as age, gender and disease duration (Glasgow et al, 1997, Hampson et al, 1990, Skinner et al, 2002). Beliefs about the *importance/effectiveness* of self-care and the perceived *threat* or *seriousness* of diabetes explained the most variance in physical activity. For example, in patients with type 1 and type 2 diabetes, exercise was predicted by the PMDI construct *treatment effectiveness* (Hampson et al, 1990, Glasgow et al, 1997, & Skinner et al, 2002) and perceived *seriousness* (Glasgow et al, 1997). In Glasgow et al's (1997) study of 2056 diabetes patients 23% of the variance in physical activity could be explained by these beliefs, after correcting for age and education. In Skinner et al's, (2002) study, exercise participation in patients with type 1 diabetes was predicted by *perceived threat* (e.g., diabetes is a serious threat to my future/current health). Finally, in a study of patients with type 1 and 2 diabetes, exercise was negatively correlated with perceived *consequences* (Cartwright & Lamb, unpublished). However, this association did not maintain significance after controlling for age in regression analyses.

The only prospective study to examine adherence to recommended physical activity was a study of (n=78) patients with type 2 diabetes and utilised the SDSCA (Hampson et al, 1995). In this study physical activity was positively predicted by perceived *treatment effectiveness* and negatively by *cause* (own behaviour).

Diet

Seven studies assessed the association between illness representations and diet in patients with diabetes. Three cross-sectional studies employed the SDSCA

which assesses eating over the last seven days (e.g., frequency of eating red meat, full-fat dairy products and fruit and vegetables). All three studies found the PMDI construct *treatment effectiveness/importance* to predict dietary intake, after controlling for age, duration of diabetes and insulin administration (Hampson et al, 1990; Glasgow et al, 1997, Skinner et al, 2002). Dietary choices were also predicted by the perceived *seriousness* and *threat* of diabetes in three cross-sectional studies (Hampson et al, 1990, Glasgow et al 1997, Skinner et al, 2002).

Again, in the only prospective study to utilise the SDSCA perceived *treatment effectiveness* positively predicted concurrent diet (Hampson et al, 1995).

The remaining studies employed different measures to assess dietary adherence. Looking at cross-sectional studies first, Griva et al (2000) assessed intentional non-adherence using items based on the Reported Adherence to Medicines Questionnaire (Horne, 2001). Dietary adherence in type 1 diabetes was correlated with *identity* and stronger *control* beliefs assessed by the IPQ (Griva et al, 2000). In a large unpublished study, Cartwright and Lamb found no significant correlations between IPQ dimensions and a measure specifically developed for the study measuring adherence to dietary recommendations in patients with type 1 or type 2 diabetes.

Finally in their prospective study Hampson et al (2000) assessed eating patterns in type 1 and type 2 diabetes patients using the Kristal Food Habits Questionnaire (Kristal et al, 1990). High-fat eating patterns were prospectively predicted by *treatment effectiveness* (e.g. importance of self-care activities) after controlling for demographic variables and medical history. Patients with stronger beliefs in *treatment effectiveness* reported fewer high-fat eating patterns (Hampson et al, 2000).

Medication

Four cross-sectional studies assessed adherence to medication in patients with diabetes. · Three of these studies (Griva et al, 2000, Cartwright & Lamb, unpublished, Glasgow et al, 1997) used adapted versions of the SDCSA. The scale includes three items on medications adherence (e.g. 'On how many of the last seven days did you take your recommended diabetes medication'?). Two of the three cross-sectional studies which used this scale later excluded this data from their analyses and do not report their findings (Hampson et al, 1990; Glasgow et al, 1997). These studies all included patients with type 2 diabetes who may not have been prescribed medication, so some questions on this scale may not have been applicable. In contrast, Skinner et al (2002) employed two questions from the SDSCA scale to assess frequency and timing of insulin injections in patients with type 1 diabetes. Results of bivariate analysis and structural equation modelling suggest that insulin administration was associated with perceived *threat* and *treatment effectiveness* to *control* diabetes. Griva et al (2000) reported that insulin adherence correlated with IPQ *control* beliefs. Thus, where data were provided, beliefs regarding *control* and *threat* were the most significant predictors of medication adherence.

Once again, the only prospective study to measure medication adherence in diabetes patients was that of Hampson et al (1995) using the SDCSA but did not report any significant findings from their analyses.

Summary

The extent of the predictive utility of the PMDI construct of *treatment effectiveness* with self-management in diabetes patients suggests that the beliefs patients hold regarding the recommended treatment of diabetes is the most important predictor of health behaviours. In addition, the perceived *seriousness* of diabetes (defined by *time-line* and *consequences*) was also prominently implicated in the extent of self-management of diabetes. However, in studies employing the IPQ and IPQ-R *control* beliefs were the most important variables in predicting adherence with self-management behaviours.

2.12. Psychological outcomes

Depression

Depression was one of the most ubiquitous psychological outcomes measured in the studies reviewed. Depression was assessed in a wide variety of disease groups including CFS, psoriasis, RA, IBS, MS, prostate cancer, diabetes and motor neurone disease (MND). Therefore, it was deemed appropriate to consider depression in these disease groups separately.

Many studies employed the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) to assess depression. The HADS consists of two sub-scales each with 7-items measuring depression and anxiety. Scores of 8-10 on either sub-scale indicate mild levels of anxiety and depression. Scores of 11 or higher on either or both of the sub-scales indicate moderate-severe symptomatology or clinically significant disorder.

Of the studies reviewed, all but one found significant associations between depression and illness representations. However, the extent of associations between representations and the consistency of the most significant components appeared to differ according to the disease studied. Cross-sectional studies are examined first.

There were two cross-sectional studies of patients with CFS. First, IPQ variables explained 28% of the variance in depression scores (Edwards et al, 2001) and only *time-line* was not significantly associated with depression. Pope and Woodcock's (2001) study assessed the influence of causal beliefs on depression in CFS and found no associations between attributions of *cause* and depression.

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In a study of 225 patients (Fortune et al, 2002), *identity* and *consequences* explained 43% of variance after controlling for age, gender and clinical history. In patients with long-standing RA, depression correlated most strongly with *consequences* (patients view their condition as serious) and *control/cure* (feel they have little *control* over their illness), even when disability was controlled for (Murphy et al, 1999).

The two cross-sectional studies of patients with irritable bowel syndrome (IBS) demonstrated some consistency. They found depression to be associated with reported *consequences* (Holt et al, 2002, Rutter & Rutter, 2002). Holt et al (2002) reported that 25% of the variance in depression scores could be explained by illness representations. Another study using path analysis demonstrated that *control* beliefs and perceived *consequences* explained 30% of the variance in reported depression (Rutter & Rutter, 2002). Despite the large sample sizes (>200) of these studies, the participants were predominantly female.
In a large study of patients with MS a number of IPQ variables (lack of *personal control, consequences* and psychological *causes*) explained 26% of the variance in depression after controlling for age and illness severity (Jopson & Moss-Morris, 2003). In a particularly small (n=17) study of patients with prostate cancer a strong illness *identity* explained 59% of the variance in HADS depression scores (Watters, 2001). Finally, a small study of patients with motor neurone disease demonstrated that a belief in more serious *consequences* correlated with higher levels of depression (Earll et al, 1993).

In the prospective studies examining the association between illness representations and depression the findings were equally diverse. First, in patients with psoriasis (Scharloo et al, 2000a), baseline *identity* explained 9% of the variance in depression scores measured at 12 months. In recently diagnosed patients with RA (< 2 years) depression could be prospectively predicted by previous assessments of perceived *consequences.* However, although initial levels of depression were controlled for, this study included only 22 patients (Sharpe et al, 2001). However, in another prospective study of long-standing RA patients (Scharloo et al, 1999), depression was predicted by symptoms (*identity*), which explained 2% of the variance (after controlling for illness duration, disease activity and baseline depression scores). Thus the results demonstrated inconsistency with regard to which components predicted depression. Overall, the results of these studies are tempered by small sample sizes. In a prospective study of patients with IBS, stronger perceived *consequences* correlated with higher levels of depression (Rutter et al, 2002) and is consistent with the findings of cross-sectional studies (Rutter & Rutter, 2002, Holt et al, 2002). However, this analysis was based on only 35 patients of which 80% were female.

Other measures of depression

In a large cross-sectional study of patients with Marfan Syndrome using the Center for Epidemiological Studies Depression Questionnaire (CES-D; Radloff, 1977) found *consequences* and *control* to be associated with depression. Patients who were more depressed perceived more *consequences* of the condition, perceived less *control* over their symptoms and were more pessimistic regarding a *cure* (Peters et al, 2001b)

Two prospective studies (Schiaffino et al, 1998, Orbell et al, 1998) used the CES-D. Both studies found that illness representations explained significant amounts of the variance in self-reported depression. However, the predictive

components were inconsistent possibly because they were time- and disease-dependent.

First, illness representations were unrelated to concurrent levels of depression in patients with RA and MS (Schiaffino et al, 1998). However, initial beliefs in the *curability* of RA as well as beliefs in one's own *responsibility* for the occurrence of RA were associated with increased levels of depression over time. For patients with MS, initial beliefs in symptom *variability* were associated with a significant increase in depression over time. The predictive components of the IPQ also changed over time in patients with OA (Orbell et al, 1998). While pre-operative depression was associated with *consequences*, post operatively 10% was explained by *control* and *consequences*. Furthermore at 9 months post-operative depression was positively predicted by *cause* (wear and tear) and lower *expectations* of surgery, accounting for 8% of the variance in depression.

Anxiety

The most commonly used measure of anxiety was the HADS anxiety sub-scale (described above). Associations between HADS anxiety and illness representations were assessed in twelve studies, exploring a variety of conditions: IBS (Holt et al, 2002, Rutter et al, 2002, Rutter & Rutter, 2002), CFS (Edwards et al, 2001, Pope & Woodcock, 2001) psoriasis (Fortune et al, 2002, Scharloo et al, 2000a), RA (Scharloo et al, 1999, MS (Jopson & Moss-Morris, 2003), prostate cancer (Watters, 2001) and MND (Earll et al, 1993). All but one of these studies (Watters, 2001) found significant associations between illness representations and anxiety, but there was less consistency in terms of which components were associated with representations, and how much variance could be explained by these factors once patient and illness-related variables had been controlled. Cross-sectional studies are examined first.

There was some consistency in the two cross-sectional studies that assessed patients' representations of IBS. Anxiety was associated with serious *consequences* in both studies (Holt et al, 2002, Rutter & Rutter, 2002). In a large

study *consequences, identity* and emotional *cause* explained 36% of the variance in anxiety scores (Holt et al, 2002). Another study using path analysis demonstrated that, *consequences* and psychological *cause* explained 41% of the variance in reported anxiety (Rutter & Rutter, 2002) (however, this result was mediated by coping variables) coping variables.

A number of illness representations were associated with anxiety in patients with CFS (Edwards et al, 2001, Pope & Woodcock, 2001). Edwards et al reported that *consequences, identity, control* and a belief in an emotional *cause* were significantly associated with anxiety explaining 30% of the variance in anxiety scores. However, the authors did not control for demographic or disease severity variables in this cross-sectional study. Pope and Woodcock (2001) also demonstrated that a belief in depression as a *cause* of CFS was associated with anxiety. In psoriasis patients Fortune et al (2002) reported that illness representations (*consequences* and emotional *cause*) explained 32% of pathological worrying and *identity* and belief in emotional *causes* explained 28% of the variance in HADS anxiety after controlling for age, gender and clinical history.

Illness representations also explained significant proportions of the variance in anxiety scores in both patients with MS. Illness representation variables (particularly *identity*, cyclical *time-line* and *coherence*) explained 23% of the variance in anxiety, after controlling for age and illness variables (Jopson & Moss-Morris, 2003. Finally, significant associations were also found in motor neurone disease (Earll et al, 1993), but not in patients a very small sample (n=17) of patients with prostate cancer (Watters, 2001).

Looking at prospective studies, Rutter et al's (2002) study of IBS patients demonstrated that perceived *consequences* was positively correlated with anxiety and confirmed findings from cross-sectional work (Rutter & Rutter, 2002; Holt et al, 2002). However, the findings of Fortune et al's (2002) cross -

sectional studies were not replicated prospectively in Scharloo et al's (2000a) study of patients with psoriasis. Moreover, no relationship was found between baseline illness representations and anxiety 12 months later. In patients with RA, anxiety was predicted prospectively by *consequences* and *time-line* beliefs which were measured one year previously (Scharloo et al, 1999); these constructs explained 10% of the variance in anxiety after controlling for illness duration, severity, coping and previous anxiety scores.

Other measures of psychological well-being

Six further scales were employed to examine the relationship between illness representations and psychological morbidity: the Mental Health Inventory (MHI; Veit & Ware, 1983) in patients with epilepsy (Kemp et al, 1999); Arthritis Impact Measurement Scale in RA (Orbell et al, 1998), health distress in MI patients (Weinman et al, 1996); the Profile of Mood States (Shacham, 1983) and Daily Hassles Scale (Revised, Holm & Holroyd, 1992) were used in patients with schizophrenia (Talley, 1998); and the Affect Balance Scale (Derogatis, 1975) was used in prostate cancer (Gonzalez et al, 2002a,b). Scores on all of these scales were related to illness representations and there was some consistency in terms of the extent of associations with well-being; five of these six studies showed that psychological well-being was predicted by *identity* and/or *consequences*. In the remaining study (Gonzalez, 2002a), *illness coherence* was associated with better mental health.

Summary

In summary, depression measured with the HADS yielded inconsistent relationships between illness representations and depression. The associated dimensions appeared to be disease- and time-specific. Overall however, *consequences*, followed by *identity* and *cure/control* appeared most important with regard to their associations with depression. The CES-D scale also yielded mixed findings but demonstrated some consistency with the HADS in that

consequences and *control* dimensions were most frequently associated with levels of depression.

Studies of anxiety yielded more consistent results. Anxiety, as measured with the HADS was most frequently associated with beliefs regarding the *consequences*, followed by psychological or emotional *causes* and perceived symptoms (*identity*) of illness. In studies employing other scales, symptoms (*identity*) and *consequences* appeared to be the most consistently associated with levels of anxiety.

2.13. Discussion

This systematic review examined relationships between illness representations and a range of clinical, behavioural and psychological outcomes in adults with chronic disease. Since the development of the IPQ (Weinman et al, 1996, Moss-Morris et al, 2002), there has been a proliferation of research employing this and other questionnaires to investigate the predictive utility of the self regulation model and illness representations framework. Therefore, the aim was to provide a comprehensive and accessible review of the literature in order to summarise developments thus far and to guide the research that constitutes this thesis. In summarising this data the focus is on the main findings; the quality, design and analysis of included studies; clinical implications of this research; and the direction of ongoing and future work in this field.

Main findings and implications

Many studies examined anxiety and depression in chronic disease and this was particularly true for arthritic conditions (Murphy et al, 1999, Orbell et al, 1998, Scharloo et al, 1999, Schiaffino et al, 1998, Sharpe et al, 2001, Tomlinson, 2001). The illness representation dimensions of *identity* and *consequences* appeared to be consistently related to psychological morbidity suggesting that it is the

perceived impact on lifestyle and the perceived symptoms that are the most important determinants of psychological distress.

With regard to coping scales, perceptions of *control* were largely associated with problem-focused strategies and may be considered consistent with the findings of Hagger and Orbell (2003) where *control* beliefs were associated with active coping and cognitive reappraisal. There was a general trend for perceived *consequences* of illness to be associated with emotion-focused strategies as were *identity* and *control.* It is suggested that the prospect of the debilitating consequences of disease gives rise to coping strategies that serve to ameliorate the emotional impact of the disease in question, such as the seeking of social support. One may also expect beliefs regarding the *control* of disease to encourage strategies that serve to engage the patient in dealing with their illness with either problem- or emotion-focused strategies. However, due to the paucity of prospective studies it remains unclear whether *control* beliefs influence the uptake of these behaviours or whether the process of dealing effectively with an illness serves to increase *control* beliefs.

With regard to the prediction of behavioural outcomes, there was little consistency across disease groups for clinic attendance and cardiac rehabilitation. However, for medication adherence perceived *consequences* was a consistent predictor in hypertensive (Brewer et al, 2002) and haemophiliac (Llewellyn, et al, 2003) patients. Finally, of particular relevance to the empirical research undertaken in the present thesis, a range of behaviours central to the management of diabetes were predicted by personal models of diabetes. This was particularly true for the *treatment effectiveness* dimension which, for example, predicted glucose monitoring (Skinner et al, 2002), physical activity and dietary recommendations (Hampson et al, 1990, Glasgow et al, 1997, Skinner et al, 2002).

Finally, quality of life outcomes particularly assessed by the SF-20 and SF-36 consistently related to perceived symptoms across many chronic diseases. In all

cases, a stronger illness *identity* (e.g. more symptoms) was associated with poorer outcomes on the SF-20 and SF-36.

Quality of studies, design and analyses

Firstly, considering the quality of the studies and data that comprise this review it is apparent that the large majority (65%) of the studies adopted cross-sectional designs. Clearly, this prohibits the determination of the direction of causality between beliefs and outcomes. Furthermore, this is often compounded by the employment of correlational, rather than multivariate analyses. Although there were some prospective/ longitudinal studies, follow-up periods were limited to a maximum of 12 months, which may be inadequate in studies of chronic disease. Of these prospective studies, none addressed the dynamic nature of illness representations by examining within-patient changes in representations over time. In addition, few studies examined differences between patients with new and long-standing diagnoses and the way in which illness representations may change over time (i.e. from diagnosis on).

Included studies were further limited by the reliance on self-report measures of adherence to treatment regimens. This approach permits over- or under-reporting due to failure of memory, understanding, or deliberate omission of the truth and as such may bias the results. Taking medication adherence as an example, when validated against objective measures such as pill counts or biochemical methods, self-report is highly variable in terms of accuracy (Francis et al, 1969). This has been observed across a range of therapies for chronic conditions including medications for hypertension (Rudd et al, 1989) and RA (Dunbar-Jacob,1993). However, studies that rely solely on clinical outcome measures (e.g., blood pressure, HbA1c) as a proxy measure of adherence may also be unreliable as a patients' condition may improve or deteriorate for a number of reasons, only one of which may be adherence.

Bivariate correlational analysis was the most common approach with regard to delineating associations between illness representations and outcomes.

However, if both correlation and regression analyses were reported in primary studies, only the results of the regression were extracted and presented in Table 2.2. Multivariate approaches were given more weight in this review as they aim to control for confounding factors such as age and disease duration. Percentage of explained variance was not reported in this review due to inconsistencies in the use of regression models (i.e., demographic and clinical control variables entered), and methods of reporting of these results between studies. Furthermore, it is argued that results of studies controlling for disease severity are more robust as patients' representations of a disease may be greater than the sum of the illness itself and subsequently may be more important in terms of determining disease related outcomes. A further point is the difficulty in determining the consistency of results emerging from the employment of different measures to elicit illness representations such as dimensions of the IPQ and PMDI. The same is also true of the measurement of some outcomes such as depression. For example, we cannot be sure that responses to the HADS-D are equivalent to that of the CES-D. The considerable range of chronic diseases comprising this review adds to the generalisability of the findings, and utility of this review. However, such diversity also restricted possible comparisons made between the studies.

One disease in which there was a degree of consistency across studies was diabetes; particularly studies employing the personal models approach to the disease. However, it is emphasised that studies employing the PMDI were authored by the members of the same research team and were often consistent regarding the selection of study outcome measures. It is clear that *treatment* beliefs and the perceived *seriousness* of the condition are important predictors of a range of self-care behaviours in this disease.

Another finding of this review was that causal attributions were not consistently operationalised across studies, and of all the illness representation dimensions, were least likely to be significantly related to the outcomes examined in this review. It is possible that the arbitrary selection of causal

items and differing methods of aggregating causal beliefs (i.e, factor analysis, 'external' v 'internal cause) may have contributed to this observation.

Limitations of the review process

Although a thorough literature search was employed, it is possible that some relevant material may have been missed. Although every effort was made to contact authors for relevant papers and data, not all responded to these requests. The included literature provided a wealth of data and it was not feasible to include all of this in the review. Indeed, the focus was solely on significant associations between representations and clinical, behavioural and psychological outcomes. This strategy highlights problems of publication bias. It is of note that many studies failed to find significant relationships between illness representations and outcomes of interest. Compounding this bias, is the well-documented notion that such studies are less likely to have been submitted for publication, or indeed accepted.

The future of illness representations research

This review clearly demonstrates the wealth of data on illness representations in chronic disease. The five 'core' dimensions feature prominently in these studies and have been useful in predicting pertinent outcomes. The emergence the IPQ-R has already made a contribution in expanding the illness representations framework beyond these five dimensions. Indeed, *emotional representations, personal control, cyclical time-line* and *illness coherence* appear to play a role in health behaviours and outcomes in a range of disease groups such as rheumatoid arthritis (Tomlinson, 2001), multiple sclerosis (Jopson & Moss-Morris, 2003), HIV (Horne et al, 2000), and prostate cancer (Gonzalez, 2002a,b). Thus the application of the IPQ-R should be encouraged in further studies.

However, although the IPQ and PMDI have demonstrated efficiency and practicality with regard to the assessment of illness representations it is

questionable to what extent they capture the true nature of living with a chronic disease. For example, the summing of items relating to the perceived *consequences* of living with a chronic condition may be viewed as a superficial assessment of what may be a complex experience. It is likely that the experience of living with a disease is a dynamic process that is inter-dependent on the extent of perceived and actual control the patient has. This experience may not be adequately captured in the form of a questionnaire. Furthermore, it is suggested that patients may have a more sophisticated or philosophical understanding of what their illness means to them and to others around them. To date there has no attempt to determine which aspects of living with a chronic disease are the most debilitating to the patient from a psychological perspective. It is argued that these issues may be clarified if patients were given the opportunity to rate how important particular perceived consequences are to them rather than summing items within a global scale (i.e., financial consequences may only be relevant to a patient if the illness had left them unable to work).

The SRM proposes that emotional responses to chronic illness are processed in parallel to illness representations which in turn give rise to problem-focused and emotion-focused coping strategies (Leventhal et al., 1984). However, studies examining the role of coping in relation to illness representations should consider a distinction between coping 'style' (i.e. dispositional, trait) and 'strategies' (i.e., situational, specific). This issue concerns Leventhals' original illness representations framework in which coping was conceptualized in a more literal sense; i.e., patients' behaviours in adjusting to a disease. Indeed, there is a tendency for researchers to misinterpret this definition of coping and have duly conceptualized coping in terms of general styles rather than specific behaviours with the application of measures which have derived from the stress and coping literature (Lazarus & Folkman, 1984). For example, with particular reference to the COPE, it is important to state that Carver et al (1989) describe the assessment of both dispositional and situational coping. Whereas the intention of the authors of the Utrecht Coping List (Schreurs et al, 1993) was

to develop a scale that assesses coping as a (personality) style rather than more general strategies. However, the original findings of Carver et al suggest that both personality traits and coping dispositions play a role in situational coping and may, therefore, be complementary in nature rather than competing. The interpretation of coping within the illness representation framework may in part explain why coping does not consistently mediate outcome in chronic disease.

It is thus argued that measures that are more akin to coping 'strategies' are more in keeping with the illness representations framework, but it may still be more appropriate to focus on coping in terms of specific behaviours (i.e., adherence to medication or diet). Finally, appraisal of coping behaviours is a neglected 'stage' of the SRM. Indeed, a patient may evaluate the efficacy of a chosen coping strategy which, if perceived as ineffective, may serve to elicit an alternative strategy or may result in a change of the representation of the illness. Therefore, more consideration should be given to emotional responses and appraisal in future research.

The results demonstrate that patients' representations can influence factors concerned with long-term health. Such evidence endorses the need to examine the amenability of changing illness representations to improve patients' physical and psychological adaptation to disease. Indeed, positive changes in illness representations following MI were demonstrated in a randomised controlled trial (Petrie et al, 2003). Thus illness representations may represent important and modifiable factors for intervention in patients with chronic disease.

Of particular relevance to the present thesis is the emergence of studies which examine the role of illness representations in significant others. For example, studies have examined differences between patient and spouses (Heijmans et al, 1999, Figueiras & Weinman, 2003), and between mothers and adolescents (Urquhart-Law, 2002). There is clearly a need to consider the congruence between the beliefs of patients and their health care providers as these discrepancies and/or similarity may prove important determinants of health

outcomes and satisfaction. The second part of this chapter examines the small body of literature that addresses these issues in detail.

To conclude, this systematic review has identified a growing body of literature that has assessed the predictive utility of illness representations framework with patients with chronic disease. The results suggest that the operationalisation of the SRM with measures such as the IPQ and PMDI have proved useful in predicting psychological, behavioural and clinical outcomes in a wide variety of chronic diseases. This, and ongoing research, illustrates the success and future potential of the self-regulatory model in understanding how patients make sense of their illness. Finally, with regard to coping behaviours, the SRM may be valuable in improving both adaptation and long-term outcomes in chronically-ill patients.

Table 2.2: Significant associations between illness representations and clinical, behavioural and psychological outcomes (cross-sectional studies)

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Brewer et al (2002)	Cholesterol control Medication adherence	Hypercholesterolaemia (N=169) Mean age 67 years 61% Male	Cross-sectional 10 based on Leventhal 1992. Self-reported pill-taking LDL cholesterol control	LDL cholesterol control => -Symptoms*, +Consequences**, -Timeline* Self-reported adherence => +Consequences*
Cartwright & Lamb (unpubl)	Self-management	Diabetes (N=186, 74 type 1, 110 type 2, 2 uncategorized) Mean age 56 62% Male Hypertension (N=176) Mean age 62 48% Male For diabetics and hypertensives: Mean age 59 (13.1) years Mean disease duration 11.6 (9.5) years	Cross-sectional IPQ Abstract Illness Perceptions Questionnaire (AIPQ; modified version of IPQ to assess general beliefs about diabetes/hypertension) Self-management questionnaire based on Bradley, 1994	Diabetes patients: Exercise ↔ -Consequences* Hypertensive patients: No significant correlations between IRs and adherence

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Earll et al (1993)	Coping Emotional outcomes	Motor Neurone Disease (N=50) 66% Male Mean age 63 years Mean disease duration 4 years	Cross-sectional Author's own measure of illness representations HADS Bradburn well-being and self-esteem scales	Anxiety ↔ +Seriousness (Consequences)* Depression ↔ +Seriousness (Consequences)** Well-being ↔ -Seriousness (Consequences)*
Edwards et al (2001)	Psychological adjustment	CFS (N=126) Mean age 43.3 63% Female Mean disease duration 62 months	Cross-sectional Questionnaire based on SRM IPQ HADS Fatigue Questionnaire	Depression => +Consequences***, +Identity**, +Cause (emotional)**, -Control/cure** Anxiety => +Consequences**, +Identity***, +Cause (emotional)***, -Control/cure* Fatigue => +Consequences***, +Identity*

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Eiser et al (2001)	Psychological well-being	Type 1 diabetes (N= 96) Mean age 47.1 (16.7) 51% Female Mean disease duration 22.5 (15) years Type 2 diabetes (N=139) Mean age 63.9 (11.3) years 56% Male Mean disease duration 12.4 (9.6) years	Cross-sectional *Well-being* Questionnaire (Bradley, 1994) *Control (Outcome* expectancies, self-efficacy) Consequences (Minimal impact, *interference)*	Total sample: General well-being => -Interference***, -Outcome expectations***, Self-efficacy** Type 1 Diabetes: General well-being => +Minimal impact**, -Interference***, -Outcome expectations*, +Self -efficacy** Type 2 Diabetes General well-being => -Interference***, -Outcome expectations*
Fortune et al (2000)	Pathological worrying	Psoriasis (N=140) Mean age 41.9 (14.2) 55% Male Mean disease duration (13.6) years	Cross-sectional IPQ Penn State Worry Questionnaire (PSWQ)	Pathological worry => +Consequences**, +Cause (emotional)*

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Fortune et al (2002)	Distress Worry Disability	Psoriasis (N=225) Mean age 43.3 (12), range 20-77 years 52% Male Disease duration 20.4 (12.9), range 0.5-54 years	Cross-sectional IPQ Psoriasis Disability Index (PDI) HADS PSWQ Psoriasis Life Stress Inventory	Disability => +Consequences*** Anxiety => +Identity***, +Cause (emotional)*** Depression => +Identity***, +Consequences*** Worrying => +Consequences***, +Cause (emotional)*** Life stress => +Identity***, +Consequences***
Glasgow et al (1997)	Self-management	Type 1 and 2 diabetes (N= 2056) 62% Female Mean age 59 years Disease duration 10 years	Cross-sectional PMDI Summary of Diabetes Self-Care Scale 31 item 'barriers' scale	Dietary intake => +Treatment effectiveness***, +Seriousness* Physical activity => +Treatment effectiveness*, +Seriousness*** Glucose testing => +Treatment effectiveness***, +Seriousness*

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Gonzalez et al (2002a)	Mood Quality of Life	Prostate cancer (prostatectomy) (N=48) Mean age 61 (5.35) years	Cross-sectional IPQ-R Affect Balance Scale SF-36	Depressed mood => - Illness coherence* Anxious mood => -Illness coherence* Guilt => -Illness coherence* Social functioning => +Illness coherence*, -Consequences*, -Emotional representations* Role limitations (physical) => -Illness coherence* General health ratings => -Consequences***, -Emotional representations**
Gonzalez et al (2002b)	Mood Physical functioning	Prostate cancer Mean age 63 (6.53)	Cross-sectional IPQ-R Affect Balance Scale SF-36	Negative affect => +Consequence**, + (Consequences x Physical Functioning)* Positive affect => -Consequences*, - (Consequences x Physical Functioning)*

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Griva et al (2000)	Adherence Metabolic control	Type 1 diabetes (N= 64) 52% Female Mean age 20.6 (4.7) years Disease duration > 1 year	Cross-sectional IPQ Generalised self-efficacy scale Self-efficacy for diabetes scale Self-report adherence scale HbA1c	Insulin ↔ +Control*** Diet ↔ +Identity***, +Control*** Blood glucose monitoring ↔ +Control*** Exercise ↔ +Control** Total adherence ↔ +Control***, -Identity** HbA1c ↔ +Identity**, +Consequences**, -Control** Total adherence => +Control*** HbA1c => +Consequences**, +Identity**
Gump (2001)	Post-operative health behaviours	Coronary artery bypass graft (N=309) Mean age 62.8 70% Male	Cross-sectional Questions based on perceptions of Cause, Control, Course and Consequences	Chi square analysis: Post-op changes in diet, exercise ↔ +Cause (diet, exercise)* Post-op changes in alcohol, smoking ↔ +Cause (alcohol, smoking)*
Hampson et al (1990)	Self-management	Type 2 diabetes (N=46) Mean age 64 years 100% Female	Cross-sectional PMDI Summary of self-care activities HbA1c	Diet => +Treatment importance **, +Seriousness* Exercise => +Treatment importance * Glucose testing => +Treatment importance*

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Heijmans (1998)	Coping Adaptive outcome	Chronic fatigue syndrome (N=98) Mean age 41.9 (10.6) years 86% Female Mean disease duration 7.44 (7.28) Mean time since diagnosis 2.46 years (2.43)	Cross-sectional Illness representations measure based on Leventhal's illness representation framework Utrecht coping questionnaire (UCL), SF36	Behavioural-avoidant coping ↔ +Identity**, +Consequences*** Cognitive-avoidant coping ↔ +Identity***, +Time-line***, -Control/cure*** Problem focused coping ↔ -Timeline**, +Control/cure**, +Cause (environmental)*** Venting emotions ↔ -Timeline**, -Consequences***, +Cause (psychological)** Seeking social support ↔ -Identity***, -Timeline***, +Cause (biological)*** Physical functioning => -Identity***, -Consequences*** Social functioning => -Consequences*** Mental Health => -Identity**, -Cause (Psychological)**, Vitality => -Identity***, Cause (Biological)**, -Consequences*

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Heijmans (1999)	Coping Functioning	Addison's disease (N=63) 57% Female Mean age 41.9, (10.6) years Mean disease duration 14.7 (11.9) years	Cross-sectional Illness representations measured by interview and items from IPQ. Coping (Utrecht coping questionnaire) Adaptive outcome (SF36)	Behavioural-avoidant ↔ +Time-line*** Cognitive-avoidant ↔ +Identity***, +Timeline** -Control/cure**, +Consequences*** Emotion venting ↔ +Identity** Physical functioning ↔ -Identity**, -Timeline**, Control/cure*, -Consequences** Social functioning ↔ -Identity**, -Timeline**, +Control/cure**, -Consequences** Mental health ↔ -Identity**, -Timeline*, +Control/cure**, -Consequences** Vitality ↔ -Identity**, -Timeline**, +Control/cure**, -Consequences**

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Helder et al (2002a)	Coping Well-being	Huntington's disease (N=77) 51% Female Mean age 51.4 (11.4) years Mean disease duration 6.4 (5.1) years, (range 1-25)	Cross-sectional IPQ (separate *cure* and *control* scales created) COPE SF-36	Mental disengagement ↔ +Identity**, -Timeline**, +Cure**, Seeking (emotional) social support ↔ +Cure**, Positive reinterpretation and growth ↔ +Control***, Physical functioning => -Identity***, Role functioning-physical => -Cure**, Bodily pain => -Identity**General health => -Identity**, Vitality => -Identity***, Mental Health => -Identity**
Hendriks (2000)	Coping Quality of life	Reflex Sympathetic Dystrophy (N=201) Mean age 46.6 years 19% Male	Cross-sectional IPQ Appraisal and coping questionnaire RAND-36 (Dutch version of the SF-36)	Emotion-focused coping ↔ +Identity**, +Timeline**, +Consequences** Problem-focused coping ↔ -Identity*, -Consequences** Quality of Life (Rand 36 Total) ↔ -Identity**, -Timeline**, -Consequences**, -Cure (by others)*, Cure (self)* Physical functioning ↔ -Identity**, -Timeline**, -Consequences** Role Functioning (Emotional) ↔ -Timeline**, -Consequences** Role Functioning (Physical) ↔ -Identity**, -Timeline**, -Consequences** Social Functioning ↔ -Identity**, -Timeline**, -Consequences** Mental Health ↔ -Identity*, -Timeline**, -Consequences** Pain ↔ -Identity**, -Timeline**, -Consequences**, -Cure (by others)* Vitality ↔ -Identity**, -Timeline**, -

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
				Consequences** General Health Perception ↔ -Identity**, -Timeline**, -Consequences**, -Cure (by others)**, Cure (by self)** RAND-36 total score => -Identit
Holt et al (2002)	Illness severity Social adjustment Psychological adjustment	IBS (N=215) 77% Female	Cross-sectional IPQ HADS Social Adjustment Scale	Illness severity => +Consequences**, Identity*, -Cause (emotional)**, -Timeline* Social adjustment => +Consequences**, +Identity* Depression => +Consequences**, +Identity* Anxiety => +Consequences**, +Identity**, +Cause (emotional)**
Horne et al (2000)	Acceptance of HAART	HIV (N=35) 97% Male Mean age 37.1 (9.27)	Cross-sectional IPQ-R	Acceptance of HAART ↔ +Identity*, +Cyclical Timeline*, +high Timeline**
Horne & Weinman (2002)	Treatment non-adherence	Asthma (N=100) Mean age 49.3 (8.1) 61% Female Mean disease duration 22.4 (18.8) years	Cross sectional IPQ Medication Adherence Report Scale (MARS)	Medication adherence ↔ -Consequences* Medication adherence => -Consequences**

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Jopson & Moss-Morris (2003)	Physical adjustment Psychological adjustment	MS (N= 168) Mean age 50 (13.02) 78% female Disease duration 11.5 (10.01) years	Cross-sectional IPQ-R HADS SIP Fatigue scale Rosenberg Self-Esteem Scale	Psychosocial impact => +Identity***, -Illness coherence*, +Consequences*, +Cause (psychological)* Role functioning => +Consequences*** Physical impact => +Identity*, +Consequences**, -Time-line* (chronic)* Mental fatigue => +Illness identity***, +Personal control*, -Treatment control*, + Consequences* Physical fatigue => +Identity***, -Personal control** Emotional responses => -Personal control*, +Consequences***, -Illness coherence***, +Cause (psychological)* Depression => -Personal control*, +Consequences*, +Cause (psychological)* Anxiety => +Identity, +Timeline-cyclical*, -Illness coherence* Self-esteem => -Personal control*, +Consequences**, -Illness coherence**, +Cause (psychological)**, -Cause (physiological)*

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Kemp (1999)	Coping Psychological adjustment	Epilepsy (N=94) Mean age 38 (16-80) years 52% Male	Cross-sectional Authors constructed an illness perceptions measure Revised Ways of Coping Checklist (WCCl-R) Mental Health Inventory (MHI)	Wishful thinking ↔ +Identity (symptoms)**, +Consequences** Avoidance ↔ +Identity (symptoms)**, +Consequences**, - Identity (label)** Problem-focused coping ↔ +Personal control** Seeking social support ↔ +Identity (label)** Psychological distress => -Identity (label)** Psychological well-being => +Self-illness (containment of disability effects)** Mental health => +Self-illness (containment of disability effects)*
Lawson et al (2004)	Clinic attendance	Type 1 diabetes (N= 42) Mean age 37.4 (10.92) years 26.2% Female	Cross-sectional IPQ PMDI COPE	IPQ: Clinic attendance => +Control* PMDI: Clinic attendance => +Treatment effectiveness***

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Llewellyn et al (2003)	Treatment adherence (Clotting factor)	Haemophilia (N=65, 44% HIV positive) Mean age =36.4 (12.2) 100% Male	Cross-sectional IPQ Adherence scores calculated by comparing individual patient treatment records with recommended regimens	Adherence to frequency of prophylactic treatment (N=32) ↔ -Identity* Adherence to recommended dose of 'on demand' treatment (N=33) ↔ -Identity*, +Consequences* ANOVA: Patients who under-treated (took less medication than recommended) had lower perceived consequences* than those who were fully adherent or over-treated
Moss-Morris et al (1996)	Coping Functioning Vitality Psychological well-being	Chronic fatigue syndrome (N= 233) 189 Female Mean age 47.8 (18-81) years Disease duration M=10.8 (8.1) years,	Cross-sectional IPQ COPE Five-item Mental Health Scale Sickness Impact Profile	SIP dysfunction => +Identity***, +Consequences** Psychological adjustment =>-Identity***, -Cause (emotional)*** Vitality => -Identity**, +Cause (emotional)**, +Control***

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Murphy et al (1999)	Depression Coping	Rheumatoid arthritis (N=62) Median age 59.5, (range 18-80) years 84% Female Median disease duration 15 years	Cross-sectional IPQ HADS London Coping with Rheumatoid Arthritis Questionnaire	Depression ↔ +Identity*, +Consequences***, -Control/Cure*** (Anxiety not reported)
Peters et al (2001)	Well-being	Marfan Syndrome (N=174) 73% Male Mean age 29.8 (12.2) years Disease duration 18.1 years	Cross-sectional IPQ Risk perception and seriousness scales Knowledge of Marfan Syndrome CES-D	Striae => + Consequences* Depression => +Consequences***, -Cure/control* Previous aortic dissection => -Cure/control*** Sore joints=> -Cure/control**
Peters et al (2001)	Adherence to health behaviours Necessity of medication	Marfan Syndrome (N=174) 73% Male	Cross-sectional IPQ Beliefs about Medicine Questionnaire (BMQ)	Exercise modification ↔ +Consequences** Necessity of medication => +Cure/control**

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Pope & Woodcock (2001)	Coping Medication adherence	Chronic fatigue syndrome (N=67) Mean age 46 (12.8) years 75% Female Mean disease duration 12.4 (8.2) years	Cross-sectional 10 causal items from IPQ HADS 45-item Illness Management Q	T-test Anxiety ↔ +Cause (depression)**
Rutter et al (2001)	Coping Quality of life	IBS (N=209) Mean age 53.5 84% Female Mean disease duration 16.9 (12.4) years	Cross-sectional IPQ COPE WHOQOL (4 quality of life events)	Active coping ↔ Cure/control*** Planning ↔ Cure/control*** Venting emotions ↔ Consequences*** Accepting of illness ↔ -Consequences*** Mental disengagement ↔ Consequences** Behavioural disengagement ↔ Consequences***, -Cure/control*** QOL ↔ Consequences, Control

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Rutter & Rutter (2002)	Coping Quality of Life	IBS (209) Mean age 53.5 84% Female Mean disease duration 16.9 (12.4) years	Cross-sectional IPQ COPE HADS WHOQOL	<u>Path analysis:</u> Quality of life => -Consequences***, Cure/control*** Satisfaction with health => +Cure/control*, -Cause (external)*, -Consequences*** Anxiety => +Cause (psychological)***, +Consequences*** Depression => +Consequences***, -Control* Acceptance coping => -Consequences** Active coping => +Cure/control*** Venting emotions => +Cause (psychological), +Consequences** Behavioural disengagement => -Cure/control*, +Consequences*** Restraint coping => +Consequences*

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Scisney-Matlock et al (2001)	Diastolic Blood Pressure (DBP)	Hypertension (N=224) Mean age 60 (12.5) years 50% Male	Cross-sectional Cognitive representations of hypertension scales	Diastolic blood pressure (DBP) => +Age x Consequences*, +Age x Control***, +Age x Timeline** Post-hoc slope analysis: Adults < 60 years: DBP ↔ -Consequences*, -Control***, -Timeline* Adults > 60 years: DBP ↔ +Control***

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Skinner et al (2002)	Self-care	Type 1 diabetes (N=338) 72% Female Mean age: men 22.2 (4.4); women: 21.8 (3.10) Mean disease duration Male = 10.7 (6.7) years; Female = 10.6 (6.1) years	Cross-sectional Personal Model and IPQ variables Diabetes Self-Care Activities Scale 'Big–Five' personality dimensions	Insulin administration ↔ +Perceived threat**, +Treatment effectiveness (to control diabetes)** Blood glucose testing ↔ +Perceived threat*, +Treatment effectiveness (to control diabetes)*, +Treatment effectiveness (to prevent complications)* Exercise ↔ +Perceived threat**, Treatment effectiveness (to control diabetes)**, +Treatment effectiveness (to prevent complications)*** Diet ↔ +Perceived threat**, +Treatment effectiveness (to control diabetes)**, +Treatment effectiveness (to prevent complications)*** <u>Structural equation modelling:</u> Insulin injections => +Perceived threat, +Treatment effectiveness (to control diabetes) Blood glucose testing => +Perceived threat, +Treatment effectiveness (to control diabetes / prevent complications) Exercise => +Treatment effectiveness (to control diabetes), +Perceived threat Diet => +Treatment effectiveness (to control diabetes)

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Steed et al (1999)	Psychosocial adjustment	Atrial fibrillation (N=62) Mean age 62 (11) years 66% Male Disease duration 5.6 (10) years	Cross-sectional IPQ COPE Psychosocial adjustment to illness scale (PAIS)	PAIS: Domestic environment => +Identity*, +Consequences** PAIS: Extended family relations => +Identity*** PAIS: Social environment => +Consequences**
Talley (1998)	Stress Mood	Schizophrenia (N=69) Mean age 44.3 54% Female Mean duration of treatment 19.2 years	IPQ Daily Hassles Scale-Revised (DHS-R) Profile of Mood States (POMS-SF)	Daily hassles ↔ +Identity***, +Consequences*** Mood ↔ +Identity***, +Consequences*
Tomlinson (2001)	Depression Pain Physical functioning Social functioning	Rheumatoid arthritis (N=104) 73% Female Mean age 60 years Disease duration 7.5 years	Cross-sectional IPQ-R Arthritis Impact Measurement Scales (AIMS)	Physical functioning ↔ +Identity***, +Consequences***, -Treatment control***, -Illness coherence*, +Timeline cyclical**, +Emotional representation***, Social Functioning ↔ Cause (pollution)***, Pain ↔ +Identity***, +Consequences***, -Treatment control***, +Emotional representations*** Depression ↔ +Identity***, +Consequences***, +Illness coherence***, Anxiety ↔ +Identity**, -Cause (own behaviour)*** Physical functioning => +Identity***, Pain => +Consequences**, Depression => +Consequences*, Anxiety => +Identity*

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Watkins et al (2000)	Health behaviours	Diabetes (N=106 type 1; N= 190 type 2) Mean age 52 years	Cross-sectional Questionnaire based on SRM	Health Behaviours => +Diabetes understanding*, +Control***
Watters (2001)	Anxiety Depression	Prostate cancer (N=17) Mean age 74.1 (4.1) years Mean disease duration 4.1 (5.2) years	Cross-sectional IPQ HADS COPE	Depression ↔ +Identity*** Symptoms ↔ +Identity** Depression => +Identity***
Wearden et al (in submission)	Well-being HbA1c	Diabetes (N=218: 134 non-insulin treated; 84 insulin treated) Mean age 60.2 (12) years 55.5% Male Mean disease duration 9.2 (8.73) years	Cross-sectional IPQ Well-Being Questionnaire (WBQ)	Anxiety ↔ +Identity**, -Timeline*, -Consequences**, +Control* Depression ↔ +Identity**, -Consequences**, +Control** Fatigue ↔ Identity**, -Timeline**, -Consequences**, +Control* Positive well-being ↔ -Identity**, +Consequences**, +Control** HbA1c ↔ +Control** <u>Diagnosis> 2 years: N=157</u> Depression => -Control**

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Wilby & Stewart (in submission)	Coping Physical functioning Psychological functioning	Stroke (N=32) Mean age 46.6 (11.7) 51% Female Mean disease duration 4.4 (4.2) years	Cross sectional IPQ COPE SF-36	Mental disengagement ↔ +Identity* Positive reinterpretation ↔ +Control/cure* Seeking (instrumental) social support ↔ +Control/cure* Behavioural disengagement ↔ -Control/cure*↔ -Control*
Whitmarsh et al (2003)	Cardiac rehabilitation attendance	MI (N=93) Mean age 63.9 (11.5) 76.3% Male	Cross sectional IPQ HADS COPE	Poor/non-attendance => -Identity***

Note: => is used to abbreviate 'is predicted by', unless otherwise stated
↔ is used to abbreviate 'is correlated with', unless otherwise stated
+ - indicates the direction of correlation or regression coefficient
x denotes interaction between variables

*p<0.05, **p<0.01, ***P<0.001

Table 2.3: Significant associations between illness representations and clinical, behavioural and psychological outcomes (prospective studies)

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Cooper et al (1999)	Cardiac rehabilitation attendance	MI: attending rehab at 6 months (N=152)	Prospective IPQ	Attendance at rehab => +Control**, +Cause (lifestyle)**
Hampson et al (1994)	Care seeking Self-management	Osteoarthritis (N=61) 28% Male Disease duration > 1 year Mean 15 years	Prospective (8 months) Personal models of arthritis interview SF-20 Summary of Arthritis Management Methods (SAMM)	Physical functioning ↔ -Symptoms*, -Seriousness**, Role functioning ↔ -Symptoms**, -Seriousness**, -Negative feelings about treatment* , Health Perception ↔ -Symptoms**, -Seriousness** Bodily Pain ↔ +Symptoms**, +Seriousness** Doctor visits ↔ +Symptoms * Osteoarthritis sources consulted ↔ +Helpfulness of treatment* <u>Concurrent (baseline) self management:</u> Typical-day management ↔ +Symptoms**, +Seriousness** Worse-day management ↔ +Symptoms**, +Seriousness** <u>Prospective self-management at 8 months:</u> Typical-day management ↔ +Baseline Symptoms*, + Baseline Seriousness* Worse-day management ↔ + Baseline Symptoms**, + Baseline Seriousness* Concurrent self-management => +Symptoms, +Seriousness Prospective self-management => +Symptoms, +Seriousness

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Hampson et al (1995)	Self-management	Type 2 diabetes (N=78) 57% Female Mean age 70 years Disease duration > 3 months	Prospective (4 month follow-up) PMDI Dementia rating scale, Summary of diabetes self-care scale HbA1c	Concurrent Diet => +Treatment effectiveness*** Physical activity => +Treatment effectiveness***, -Cause* Diet at 4 months => +Treatment effectiveness *** HbA1c => -Cause (own behaviour), -Treatment effectiveness
Orbell et al (1998)	Functional activity Depression	Osteoarthritis (N=72) (joint replacement of the knee or hip) Mean age 68.2 (9.05) years (range 43-85) 60% Female Mean disease duration 71 (96.7) months	Prospective (3 and 9 months) Illness representation measure based on qualitative pilot work CES-D 32-item functional activity measure derived from qualitative work	Depression (pre-operative) => +Consequences**, -Control* Depression (3 months post-operative) => +Consequences*, +Control** Depression (9 months post-operative) => +Cause (wear and tear)**, -Expectations of surgery** Functional activity (pre-operative) => -Consequences* Functional activity (9 months post-operative)=> -Cause (ageing)*, +Control**

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Petrie et al (1996)	Prediction of rehabilitation attendance	First time MI patients (N=143)	Prospective IPQ: Identity, Cause, Control, Consequences	Return to work => -Timeline*, -Consequences**
Rutter (2002)	Psychological morbidity Quality of life	IBS (N=35)	Prospective (2 months) IPQ HADS	Anxiety ↔ +Consequences Depression ↔ +Consequences Quality of Life ↔ +Consequences Dissatisfaction with health ↔ +Consequences
Searle & Murphy (2000)	Treatment adherence	Homoeopathic patients with chronic illness (N=30) Mean age 39 (11.7) years 79% Female	Prospective (2 month follow-up) IPQ Authors' own self-report scale for adherence and understanding.	Adherence to remedies => +Identity**, -Cause-pollution*, -Cause-own behaviour***, +Cause-poor past care* Non-adherence (use of non homoeopathic medication) => +Consequences*, -Cause-other people*, -Cause-own behaviour***, +Cause-chance* Adherence to diet => +Cause (poor past care)*, +Cause (chance)*

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Sharpe et al (2001)	Depression	Rheumatoid arthritis (N=22) 70% women Age 55.6 (14.1) Disease duration < than 2 years Mean illness duration 12.63 months (8.22)	*Prospective* IPQ HADS-D Coping Strategies Questionnaire (CSQ)	Time 3 Depression => +Consequences* Time 5 Depression => +Consequences** Time 6 Depression => +Consequences*
Scharloo et al (1999)	Physical functioning Psychological functioning	Rheumatoid arthritis (N=71) Mean age 52.2 (12.2) years 75% Female Disease duration 12.4 (8.5) years	Prospective (1 year follow-up) IPQ, HAQ, UCL Hospital appointments HADS	Clinic visits => +Consequences*** Hospital admissions => -Control/cure*** Anxiety => +Consequences***, +Timeline*** Depression => +Identity*** Pain (HAQ) => Identity** Tiredness (HAQ) => +Identity**, +Consequences**

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Scharloo et al (2000a)	Physical functioning Psychological functioning	Psoriasis (N=69) Mean age 48.3 (13.4) 65% Female Disease duration 26.6 (15.4) years	Prospective (Baseline and 1 year) Interview prior to IPQ Coping (Utrecht coping list; UCL) HADS Functional status (SF20)	Hospital visits => +Baseline Control/cure**, +Baseline Identity***. Physical functioning at 1 year => -Baseline Identity*** Social functioning at 1 year => -Baseline Identity*** Depression at 1 year => +Baseline Identity*** Social functioning => -Baseline Identity*** Mental Health at 1 year => -Baseline Identity*** Health perceptions at 1 year => -Baseline Consequences**
Scharloo et al (2000b)	Physical functioning Psychological functioning	COPD (N=64) Mean age 63.8 (7.7) years 77% Male Disease duration =12.2 (12.1) years	Prospective (Baseline and 1 year) Interview prior to IPQ UCL SF20	Social functioning at 1 year=> - Baseline Identity*** Health perceptions at 1 year => - Baseline Identity*** Clinic visits at 1 year => -Baseline Cause (stress, other people as causes)**

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Schiaffino et al (1998)	Psychological adjustment	Rheumatoid arthritis (N=63) Mean age 53 (14) years 90% Female MS (N=66) Mean age 42 (12) years 90% Female	Prospective (4 months) IMIQ CESD-20 Functional status subscale of AIMS	RA: Initial illness severity ↔ -Variability* Later depression ↔ +Cure*, +Responsibility** Later depression => +Cure*, +Responsibility*, +Severity x Consequences* MS: Initial illness severity ↔ +Consequences*** Later depression => +Variability*

Authors/Year	Outcomes	Patients	Design and Measures	Significant results
Weinman et al (1996)	Disability Sickness impact Distress Recovery beliefs	Discharged MI patients (N=104) 87% Male Mean age 53.8 (8.2) years Mean disease duration 3 months Discharged MI (N= 91) 88% Male Mean age 53.5 (8.1) years Mean disease duration 6 months	Prospective (3 & 6 month) IPQ Sickness Impact Profile Recovery Self-Efficacy Scale	<u>3 month follow-up measures ↔ 3 month IPQ (N=104)</u> Disability ↔ +Identity***, +Timeline*, +Consequences***, Doctor visits ↔ +Identity**, +Consequences*, Health distress ↔ +Identity**, +Timeline*, +Consequences***, Self-rated health ↔ -Identity***, -Timeline**, -Consequences** , Perceived likelihood of future MI ↔ +Identity*, +Timeline**, +Consequences***, -Control/Cure***, Control over heart problems ↔ -Identity**, -Timeline***, -Consequences***, +Control/cure*** <u>3 month follow-up measures ↔ Baseline IPQ (N=104)</u> Self-rated health ↔ -Identity*, -Consequences* Doctor visits ↔ +Consequences*, Perceived likelihood of future MI ↔ -Timeline*, +Control/cure***, Control over heart problems ↔ -+Control/cure*** <u>6 month follow-up measures ↔ Baseline IPQ (N=115)</u> Likelihood of future MI ↔ +Timeline**, +Consequences*, +Control/cure*, Control over heart problems ↔ +Control/cure**

Note: => is used to abbreviate 'is predicted by', unless otherwise stated
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+ - indicates the direction of correlation or regression coefficient

*p<0.05, **p<0.01, ***P<0.001

2.14. Illness representations and significant others

The first part of this chapter systematically reviewed the literature examining the role of illness representations with regard to clinical, behavioural and psychological outcomes in chronic disease. However, recent developments in the application of the self-regulatory model of illness behaviour have been directed at exploring the relationship that significant others such as partners, or other carers of patients with chronic disease, have on disease outcomes. Weinman et al. (1996) suggest that it may be equally important to focus on perceptions of the spouse and other key 'caregivers' to obtain new insights into the role of partners or carers in the patient's recovery process. It is this small, but growing, literature that is examined in the narrative review that follows.

Significant others and chronic disease

Little is known about how social interactions affect patients' views about chronic disease and their corresponding health behaviours. However, research suggests that not only the supportive interactions themselves but also the beliefs held by people within a patients' social network may influence the patients' illness representations and health related behaviour (Heijmans et al, 1999). Empirical support for this assumption has been provided by Croyle and Hunt (1991), who found that individuals may even rely on a relative stranger when attempting to evaluate the seriousness of an ambiguous health threat.

Although spouses generally appear to be the most important source of 'emotional' and 'instrumental' support for many patients with chronic disease (Thompson and Pitts, 1992), it is obvious that patients' and spouses' ideas about an illness may diverge. In comparing patients' and spouses' illness representations it is possible that differences between patients' and spouses' illness representations might go in two directions. For example, spouses may minimise the seriousness of their partners' disease, by playing down the complaints and *consequences* of the illness or by exaggerating the possibility for

cure. Conversely, spouses may exaggerate the seriousness of the disease and become overprotective.

Accordingly, expression of maximisation or overprotective behaviour by the spouse has been found to negatively affect patients' well-being (Thompson & Pitts, 1992). It may also favour sick-role behaviour on the part of the patient and leads to negative consequences for the patient such as increased dependency, lowered competence, and depression (Nerenz & Leventhal, 1983; Thompson & Pitts, 1992). However, the magnitude of the effects of 'minimisation' or 'maximisation' by the spouse may be moderated by factors relating to the disease itself such as its symptoms, course and how amenable it is to treatment in addition to the quality of the patient-partner relationship.

Dissimilarity in patients' and partners' illness representations

Heijmans et al. (1999) investigated whether differences in illness representations expressed as either 'minimisation' or 'maximisation' of the disease by the spouse affects the patients' coping behaviour and adaptive outcome in 52 patients with Addison's disease (AD) and 49 patients with Chronic Fatigue Syndrome (CFS). The two diseases were selected by the authors as they share similar symptomatology but differ in their aetiology. AD is characterised by adrenal insufficiency resulting in symptoms of fatigue, weakness and weight loss. However, AD can be adequately managed by medication. Chronic Fatigue Syndrome resembles AD in its most important symptom, debilitating fatigue. However, CFS patients have to cope with an illness for which there is no diagnostic test or effective treatment.

In this study the authors measured patients' and spouses' beliefs using the 5 'core' dimensions of illness representations; *identity, time-line, consequences, control/cure* and *cause*. Illness identity was measured with a 20-item symptom list considered typical for CFS and AD, these included 12 symptoms taken from

the original IPQ and 8 items central to the medical definitions of the respective illnesses. Internal reliability for the *identity* scale was 0.75 for both diseases and patient-partner dyads. The *cause* dimension was measured by 15 items related to the possible causes of the illness. Factor analysis with varimax rotation identified three scales referring to a belief in a 'biological' *cause* (virus, flu, immune dysfunction), a 'psychological' *cause* (stress, personality, depression) and an 'environmental' *cause* (chemicals, malnutrition, pollution). Together the *three scales explained* 52% of the variance and yielded good reliability (α = 0.70). Internal reliability for the *consequences* (5-items) scale was also good for both diseases and patients and spouses (α = 0.70). The *time-line* scale (3-items) had lower reliability for CFS patients and their spouses (α = .059 and α = 0.58) but was satisfactory for AD patient and their spouses (α = 0.70). Finally, the *reliability of the control/cure* scale (2-items) was satisfactory for CFS patients and their spouses (α = 0.70) but less so for AD patients and their spouses (α = 0.54 and α = 0.63).

The quality of the marital relationship was measured from the perspective of the patient with three scales assessing 'satisfaction', 'burden on the spouse', and 'social support'. Coping was assessed with the Utrecht Coping Questionnaire (Schreurs et al., 1993) using the problem-focused, emotion-focused and palliative coping sub-scales. Adaptive outcome was assessed with the Short-Form Health Survey (Ware & Sherbourne, 1992) with specific reference to the Physical and Social Functioning, Mental Health and Vitality scales.

Both the CFS patients and AD patients reported high levels of satisfaction with their marital relationship but felt differently about the burden their illness created for their spouses. The CFS patients believed their spouses were less accepting of their illness and as a consequence criticized their management of the illness. They also differed in the extent to which they felt supported by their spouses with the CFS patients being less happy than the AD patients in this regard.

No significant differences were found between mean scores for the CFS patients and their partners on the *identity, control/cure,* or *cause* dimensions. At a group level patients with CFS and their partners appeared to agree on the *identity* of the illness and possibility for *cure.* There was also some agreement regarding the *cause* of the condition with both parties predominantly believing in a 'biological' *cause.* However, there were differences with regard to the *consequences* and *time-line* dimensions. Indeed, compared with partners, patients perceived more *consequences* of CFS but believed their illness would improve in time. The AD patients were more optimistic about the course of their illness than their partners and were more convinced that they could control it either by treatment or their own behaviour. The partners of AD patients rated the *consequences* of the illness more seriously than patients.

Scores of dissimilarity were calculated for the illness representation dimensions for each dyad by subtracting the partner's score from the patient's score. This procedure provided a continuous variable that describes the direction of difference from the spouses' framework (i.e., as 'maximising' or 'minimising' relative to the patients' ratings). In general, the dyads held similar views with regard to the dimensions of illness *identity* and *cause* but disagreed on the *time-line, control / cure* and *consequences* of the illness. However, the partners of CFS and AD patients held more pessimistic views with regard to the *time-line* of the illness than patients themselves. They were also shown to think differently from the patients with regard to symptoms, *consequences* and possibilities for *cure* of the illness. For example, the partners of patients with CFS were inclined to 'minimise' the seriousness of the illness on these dimensions, while the partners of patients with AD had a tendency to 'maximise' or exaggerate the seriousness of the disease.

More specifically, for patients with AD, minimisation of the possibilities for *cure* by the partner explained 26% of the variance in palliative coping. For patients

with CFS, 'minimisation' by the partner regarding *consequences*, a belief in environmental factors as a *cause* and a more pessimistic *time-line*, accounted for 32% of the variance in palliative coping. Patients' and partners' illness representations were more predictive of adaptive outcome when dissimilarity was high, when the partner had a more pessimistic belief about the *time-line* of AD, and with patients exhibiting higher scores on the Physical and Social functioning, Mental Health and Vitality scales. For patients with CFS, minimisation of the symptoms of illness and the partners' attributions of psychological and environmental factors as causal agents resulted in more problems in psychological adjustment.

In summary, minimisation of the seriousness of the disorder by the partner was found to have a negative impact on adaptive outcome, although this observation varied between the dimension of the illness representation and the type of illness.

Patients and spouses causal attributions of myocardial infarction

Weinman et al, (2000) examined attribution (perceptions) of cause in first time MI patients and their partners to examine how such attributions related to changes in patients' health behaviours (diet, exercise, and smoking) 6 months later. It was postulated that the process of searching for a cause of the illness was not limited to patients but also common in spouses and others close to the patient (Taylor et al, 1984). Studies examining the attribution of spouses following MI have found a similarity between the types of attributions made by both spouses and patients (French et al., 2001). Many studies in the cardiac area have highlighted the importance of the patient's spouse in the recovery phase and in longer-term progress (Taylor et al., 1984). Turnquist et al., (1988) proposed that people who make more attributions are more likely to be distressed. Hence, Weinman and colleagues investigated the number of causal attributions held by patients and spouses, and whether these were related to

their perceptions of the severity of the MI and their spouses' fear of a further MI.

Patients and their partners (n=143) were presented with a list of 24 possible causes for their / partners' MI. Patients and their spouses also completed subjective self-ratings of their own / their partners' health compared to a person in excellent health, and spouses were also asked to rate how afraid they were that there partner would have another heart attack in the next year.

The results of the study demonstrated that causal attributions are important predictors of subsequent changes in health behaviour following MI. The majority of MI patients made significant changes in their health behaviours. For example, patients who believed their MI was caused by poor health habits were more likely to make changes in their diet than those who believed their MI to be caused by 'stress' or 'hereditary' factors. It was also demonstrated that spouses' attributions about the MI being caused by poor health habits were the most important factor in improvements in levels of exercise at 6- month follow-up. Furthermore, the number of attributions varied as a function of the perceived severity on the part of the patient and greater anxiety on the part of the spouse regarding the occurrence of a further MI. However, objective markers of severity (peak creatinine phosphokinase level and length of hospital stay) were not related to the attributions made by the patient or spouse.

Partners representations and recovery from myocardial infarction

In a further examination of the role of illness representations in spouses of patients with mycocardial infarction, Figueiras and Weinman (2003) examined whether similar patient and spouse perceptions were predictive of recovery. A total of 70 patient-partner dyads recruited from a Lisbon hospital completed a Portuguese translation of IPQ at 3-months after discharge from hospital. A reworded version of the measure was used to assess the spouses' perceptions of

the patient's MI. The perceived identity of MI was assessed with a list of 15 general symptoms yielding alpha coefficients of 0.83 and 0.73 for patients and partners, respectively. The internal reliability of the *consequence* (7-items) scale was 0.73 and 0.73, and *control/cure* (8-items) with alphas of 0.62 and 0.73 for patients and spouses, respectively. Perceived *time-line* was assessed with one item.

Recovery was assessed at intervals of 3, 6 and 12 months post MI using standardised measures taken from the medical outcome study and using some of the items from the Portuguese SF-36 (Ferreira, 2002, a, b) including 'physical disability', the 5-item mental health index (Viet and Ware, 1983), the 'vitality' scale of the MOS energy-fatigue scale (Stewart et al., 1988). In addition, scales from the sickness impact profile assessing social activities and recreations were completed along with a measure of eating behaviour assessing seven dietary items (fried food, bran, salt sugar, red meat, fruit and breakfast). Finally, marital functioning was assessed with appropriate items from the MOS (Sherbourne and Kamberg, 1992) to assess the quality of the relationship with their spouse during the previous 4 weeks.

A comparative patient-partner score was developed which attempted to take account of not only the degree of similarity of their perceptions but also the relative level (i.e., high / low) of the scores on each dimension of the IPQ.

A classification system based on the median score for each group (patient, partner) was devised to identify the extent that an individual's illness perception was broadly positive (e.g., above the median group score on *control*) or negative (below the median). Thus patients' and partners' scores on each of the four dimensions (*identity, consequences, time-line* and *control*) were recoded according to the median split for each variable. Therefore, scores for patients and partners that fell below the median for each respective group were coded '0' and scores above the median were coded '1'. Three broad groupings were then derived; (1) 'similar positive' perceptions (where both patient and partner score is '0' for *identity, consequences* and *time-line* and both score '1' for *control*),

(ii) 'similar negative' perceptions (where patient and partner both score '1' for *identity, consequences* and *time-line* and both score '0' for *control*), finally (iii) 'conflicting' perceptions were where patients and partners had conflicting scores (patient scores '1' partner scores '0' or vice versa).

The highest percentage of couples with similar 'positive' perceptions were found on the *identity, time-line* and *consequences* dimensions of the IPQ whereas a greater frequency of similar 'negative' and conflicting perceptions were found on the *control/cure* dimension. Patients' recovery from MI was favoured in dyads with similar 'positive' perceptions of *identity* and perceived *consequences,* compared with dyads with similar 'negative' or 'conflicting' perceptions. The patients from dyads with similar 'positive' perceptions of *identity* and perceived *consequences* of MI reported lower levels of disability and less sexual problems, higher vitality, less health distress, better psychological adjustment, and less impact of MI on recreational and social activities. On the basis of these results the author's assert that various aspects of recovery from MI are associated with the degree of congruence between patients' and spouses' perceptions of MI.

Dissimilarity of adolescent and maternal representations of diabetes

Urquhart-Law (2002) examined dissimilarity in adolescent and maternal representations of type 1 diabetes with regard to adolescent well-being. The study was undertaken in the absence of explanatory models by which the family may influence a child's or young person's adjustment to illness. Indeed, little is known about how illness representations form and how social interactions affect patients' beliefs and subsequent behaviours. In this context, it was suggested that the mechanisms by which parents influence their child's chronic illness is by influencing or shaping illness representations and health related behaviour (Lau et al, 1990).

A sample of 30 adolescents aged between 13 and 19 years (Mean = 15.5 years) with a diagnosis of type 1 diabetes were recruited to the study along with 26

mothers (mean age 43 years). The IPQ-R was used to elicit illness representations with the addition of items to three sub-scales; *identity, consequences* and *emotional representations* scale. Wording on the maternal IPQ-R was based on the advice of the original authors (i.e., 'my diabetes....' was replaced with 'my son/daughter's diabetes. Psychological well-being was assessed with a 22-item self-report measure developed specifically for diabetic populations consisting of four sub-scales measuring depression, anxiety, positive well-being and perceived energy (Bradley, 1994).

The adolescents perceived their diabetes to be chronic with high levels of *personal control* over their illness. They also demonstrated positive beliefs regarding *illness coherence* and *emotional representations* of diabetes. Maternal representations were broadly similar but mothers were likely to perceive more severe *consequences* and a greater *emotional representations.* Scores of dissimilarity were computed for each adolescent-mother dyad by subtracting the mother's score from the adolescents score. This procedure created a continuous variable describing the direction of difference from the mother's framework, (i.e., as either 'maximising' or 'minimising' relative to the adolescent's ratings). Mothers had a tendency to maximise the seriousness of diabetes on a number of dimensions; they reported worse *consequences,* less *illness coherence,* greater *emotional representations,* and greater variability in the course of their son/daughter's diabetes. They also perceived adolescents as having enhanced *personal control* over their illness. There were no correlations between the illness representation dissimilarity scores and adolescent well-being.

Due the cross-sectional nature of the study it is not possible to determine the process of mutual influence over time. This would have assisted in delineating the dynamic interplay between the illness representations of mothers and adolescents. In addition, it is not possible to determine whether adolescent representations were more strongly guided by maternal beliefs or vice versa.

Equally plausible is the option that each is influenced by some other source such as paternal or peer representations. Finally, the small sample size limited the power and ability to detect differences between adolescents' and mothers' representations. Nonetheless, the study has shown how adolescents' and mothers' representations may converge or diverge in relation to diabetes.

Illness representations in carers of stroke victims

Studying the illness representations of spousal caregivers may contribute to understanding how spouses cope with caring for a chronically ill partner and discovering if and how the quality of life of spouses is affected by their care-giving responsibilities.

Illness representations were assessed in a cross-sectional investigation of the determinants of distress in 86 primary carers of people with non-acute and non-aphasic stroke (McClenahan and Weinman, 1998). The carers primarily consisted of spouses. In addition, 53 patients with left hemisphere CVA with aphasia and 33 patients with right CVA and no aphasia participated in the study. The IPQ was adapted specifically to assess the carer's perception of the stroke. This amended version was then factor analysed for subsequent analyses. In addition, a range of other constructs relating to self-efficacy social support, and coping were assessed.

Distress in carers was assessed with the General Health Questionnaire 12 (GHQ 12; Goldberg, 1992), a screening measure designed to detect psychological distress in non-clinical populations. In order to assess whether carer distress was related to dispositional factors including illness representations a series of correlations were conducted between these measures. For illness representations only the *time-line* dimension was related to distress scores. The *time-line* variable was then entered into a regression analyses alongside other correlated constructs such as self-efficacy and coping variables. In total the

independent variables explained 45% of the variance in distress experienced by carers.

Illness representations in carers of patients with Huntington's disease

In a cross-sectional study, Helder et al (2002b) examined representations of spouses of patients with Huntington's disease (HD) with regard to their quality of life and coping mechanisms. A total of 90 spouses (54% female) were assessed with an adapted version of the IPQ. Spouses were asked to report their views with regard to the patients' HD. A further amendment was made to the *control* sub-scale by dividing it into two separate scales; *cure* and *control*. The internal reliability coefficients of the scales reached 0.66 and 0.83, respectively. The *consequences* and *time-line* sub-scales from the IPQ were utilised in their original form with reliability coefficients of 0.63 and 0.81, respectively. Finally, with regard to *identity*, spouses rated how often the patient with HD experienced a list of 19 somatic symptoms on a 4-point scale ranging from 1 (never) to 4 (all the time), yielding an internal reliability coefficient of 0.86. The coping mechanisms of spouses were assessed with COPE (Carver et al, 1989) and quality of life was assessed with the MOS SF-36 (Ware & Sherbourne, 1992).

The results showed that spouses scored highly on the *identity* sub-scale of the IPQ. In addition, they perceived HD as having a long *time-line*, with negative *consequences* without much possibility for a *cure* or *control* of the symptoms. All spouses, with the exception of two, attributed HD to a genetic cause. Correlational analyses showed that the more seriously the illness was perceived by the spouse in terms of the number of symptoms (*identity* and *time-line*) the less the spouse was inclined to use 'denial' as a coping strategy. The spouses perceived the *control* that patients had over their disease was related to the adoption of 'restraint' coping activities. Finally, the more spouses believed in a *cure* for HD the less they focused on and vented their emotions as a way of coping with the disease. However, when demographic and disease-related

variables were controlled in regression analyses, none of the IPQ variables explained variance in quality of life. The way in which spouses of patients with HD perceive HD seems not to influence their own quality of life. The authors suggest that this measure of illness representations was possibly too global as spousal representations were not assessed with regard to the specific consequences of living with and caring for a partner with HD.

Illness representations in carers of patients with Alzheimer's disease

Roberts and Connell (2000) utilised the illness representation framework among first-degree relatives of people with Alzheimer's disease. Illness representations were assessed with scales developed for the study rather than using existing scales such as the IPQ. The scales assessed beliefs regarding *knowledge, causes, treatment, distress,* and *threat* of Alzheimer's disease and were refined in a pilot study of 200 individuals. Of the 203 participants, 75% were female and 73% were married. The results demonstrated that participants were better informed about AD than the general public. With regard to *cause,* participants rated genetic factors as the most important cause of Alzheimer's which is consistent with conventional medical wisdom. However, 34% of participants endorsed beliefs in potential environmental factors such as diet/lifestyle and mental inactivity as a possible *cause* suggesting some belief in personal control over the onset of Alzheimer's. Further, a third of carers believed that God's will was very important in the development of the disease. With regard to treatment beliefs, 65% of participants believed that there would be a cure in the next 5 years. The distress experienced through having a relative with Alzheimer's manifested itself in the form of 'intrusive thoughts', 'intense emotions' and 'intrusive imagery' and a quarter reported sleep difficulties. A significant number considered that they were somewhat (40%) or very likely (35%) to develop Alzheimer's in the next 5 years. However, only 34.5% reported that they were more concerned about Alzheimer's than any other medical problem. Finally, more than 75% of participants reported that both the emotional and financial consequences of developing Alzheimer's would be at

least very stressful, with a quarter of respondents anticipating such an outcome would be overwhelmingly stressful for them and their families.

Illness representations in carers of patients with Schizophrenia

In a departure from the literature considering chronic physical disease Barrowclough et al. (2001) investigated models of illness in carers of patients with schizophrenia. The rationale for this study was to assess how the carer's response to the patient's illness mediates illness outcome in schizophrenia.

A total of 47 carers were recruited into the study, of these 53% were parents, 28% were spouses, 11% were siblings and the remaining carers were either children of the patient (4%) or had another relationship with the patient (4%). Most carers were female (68%) and living with the patient.

Carers' representations of schizophrenia were assessed with a modified version of the IPQ to accommodate the nature of schizophrenic illness and to examine the impact of the patients' illness from the perspective of the carer. First, the *identity* sub-scale of the IPQ was replaced with the 'Family Questionnaire' (Barrowclough & Parle, 1997). This scale lists 45 problems associated with schizophrenic illness. The carer was asked to rate these problems on three scales; 'frequency', 'coping' and 'concern'. The *time-line* dimension was modified to capture the fluctuating or episodic nature of the illness (2 items, α= 0.60) as well as including the original IPQ version to focus on the chronicity of the illness (3 items, α= 0.53). Additionally, to assess the *consequences* and *control/cure* dimensions from the carers' perspective, two additional scales containing 'parallel' items were included (*consequences-relative* (α= 0.78) and *control/cure-relative* (α= 0.61). For example, the parallel item for 'Their illness has major consequences on their life' was 'Their illness has had major consequences on my life'. Finally, as it was the carers' rather than the patients' representations that were assessed, minor modifications were made to the wording of all items of the sub-scales (e.g., 'my illness' became 'their illness'. The internal reliability of the modified IPQ was considered acceptable with

reliability coefficients of 0.68 for *control/cure* (6 items) and 0.71 for *consequences* (7-items). Additionally, test-retest reliability at 2 weeks using a sub-sample of 16 participants demonstrated significant positive correlation's for all sub-scales ($p < .01$) with *consequences* being the most stable dimension.

Carer functioning was assessed with the GHQ (Goldberg, 1978), the Beck Depression Inventory (BDI; Beck 1988) and the distress sub-scale of the Social Behaviour Assessment Schedule (SBAS; Platt, 1985). Symptom severity in patients was assessed with the Positive and Negative Syndrome Scale (PANSS; Kay et al, 1989) and social functioning with the Social Functioning Scale (SFS; Birchwood et al, 1990, using the carer as the informant. Finally, general functioning was assessed with the Global Assessment Scale (GAS; Endicott et al, 1976).

Correlational analysis demonstrated that greater perceived negative *consequences* for the patient was associated with a higher psychological morbidity in the carer. Perceived negative *consequences* was also consistently associated with adverse carer outcomes including higher psychopathology, depression and subjective burden. Problems relating to the symptoms of schizophrenia were associated with higher scores for carer distress. The dimensions of *control/cure* and *control/cure*-relative were not associated with any carer outcome measures. Analysis was also conducted to determine if carer representations were associated with functioning in the patients. A different pattern of associations emerged from that seen with carer functioning analyses. There were no associations between patient functioning and perceived *consequences* of the illness. However, the chronic *time-line* and the *identity-symptom* scores were associated with patients' illness characteristics. For example, a longer *time-line* was associated with a longer duration of patient illness, a higher PANSS score, and lower scores on the GAS (indicating less adaptive functioning) and the social functioning scale. Similarly, a greater

number of symptoms were associated with a higher PANNS score and poorer social functioning.

The findings demonstrate that links exist between illness representations and assessments of carer and patient outcomes. While there were significant associations between measures of the illness characteristics and carers' perceptions of illness *identity* and *time-line*, the *consequences* and *control/cure* dimensions showed no association to the measures. The well-being of carers was mainly related to perceptions of the magnitude of the *consequences* of the illness for themselves. The authors suggest that the components of illness representation found to be important in models of physical illness cannot be assumed to be important in mental illness-there may be other dimensions of illness cognition that are of equal or greater importance in schizophrenia.

Table 2.4. Summary of studies examining the illness representations of significant others.

Authors / Year	Objectives	Participants	Design & Measures	Relevant findings
Heijmans et al, (1999)	To examine the extent of dissimilarity in patients' and spouses' representations of CFS and Addison's disease in relation to patient adaptation	49 patients with CFS and spouses 92 % female Mean age= 40.4 years 52 patients with Addison's disease and spouses 72% female Mean age = 43.5 years	Cross-sectional IPQ Utrecht coping questionnaire SF-36	Differences were found for the consequences and time-line dimensions. Patients perceived more consequences of CFS than partners but believed their illness would improve in time. Partners of patients with CFS were inclined to 'minimise' the seriousness of the illness while partners of patients with AD had a tendency to 'maximise' or exaggerate the seriousness of the disease. For patients with AD, minimisation of cure by the partner explained variance in palliative coping. For patients with CFS, 'minimisation' by the partner regarding consequences, cause and perceived time-line, accounted for 32% of the variance in palliative coping. Illness representations were more predictive of adaptive outcome when dissimilarity was high, when the partner had a more pessimistic belief about the time-line of AD, and with patients exhibiting higher scores on the Physical and Social functioning, Mental Health and Vitality scales. For patients with CFS, minimisation of the symptoms of illness and the partners' attributions of psychological and environmental factors as causal agents resulted in more problems in psychological adjustment.

Authors / Year	Objectives	Participants	Design & Measures	Relevant findings
Weinman et al, (2000)	To assess causal attributions in patients and spouses following first time MI in relation to subsequent lifestyle changes	143 first-time MI patients 87% male Mean age= 53.2 years 84 spouses	Prospective (outcome assessment at6 months) Attributions of cause assessed with a list of 24 possible causes of MI Diet Physical activity	Causal attributions are important predictors of subsequent changes in health behaviour following MI. The majority of MI patients made significant changes in their health behaviours. For example, patients who believed their MI was caused by poor health habits were more likely to make changes in their diet than those who believed their MI to be caused by 'stress' or 'hereditary' factors. It was also demonstrated that spouses' attributions about the MI being caused by poor health habits were the most important factor in improvements in levels of exercise at 6- month follow-up. Furthermore, the number of attributions varied as a function of the perceived severity on the part of the patient and greater anxiety on the part of the spouse regarding the occurrence of a further MI.
Figueiras & Weinman, (2003)	To examine whether the degree of congruence between the patient's and the partner's perceptions of MI influence recovery	70 patient-partner dyads experiencing first time MI Mean age of patients = 53 years; spouses=50 years	Prospective (outcome assessment at 6 and 12 months) Portuguese translation of IPQ SF-36 MOS energy-fatigue scale Mental Health Index Sickness Impact Profile Diet	The highest percentage of couples with similar 'positive' perceptions were found on the identity, time-line and consequences dimensions of the IPQ A greater frequency of similar 'negative' and conflicting perceptions were found on the control/cure dimension. Patients' recovery from MI was favoured in dyads with similar 'positive' perceptions of identity and perceived consequences, compared with dyads with similar 'negative' or 'conflicting' perceptions. The patients from dyads with similar 'positive' perceptions of identity and perceived consequences of MI reported lower levels of disability and less sexual problems, higher vitality, less health distress, better psychological adjustment, and less impact of MI on recreational and social activities.

Urquhart-Law, (2002)	To compare the illness representations of adolescents and their mothers and their relationship with psychological adjustment	30 adolescents (mean = 15.5 years) with type 1 diabetes Mean disease duration= 4.9 years 26 mothers (mean age 42.7 years)	Cross-sectional Adapted IPQ-R Well-being Questionnaire (Bradley, 1994)	Mothers maximised the seriousness of diabetes; worse consequences, less illness coherence, greater emotional representations, and greater variability in the course of their son/daughter's diabetes. Also perceived adolescents as having enhanced personal control over their illness. There were no correlations between the illness representation dissimilarity scores and adolescent well-being.
Helder et al, (2000b)	To describe the illness representations and coping mechanisms of spouses of patients with HD.	90 spouses of patients with HD 54% female Mean age = 53 years	Cross-sectional Adapted 'spouse version' of IPQ COPE SF-36	Spouses scored highly on the identity sub-scale and perceived HD as having a long time-line, with negative consequences without much possibility for a cure or control of the symptoms. Correlational analyses showed that the more seriously the illness was perceived by the spouse in terms of the number of symptoms (identity and time-line) the less the spouse was inclined to use 'denial' as a coping strategy. The spouses the perceived control that patients had over their disease was related to the adoption of 'restraint' coping activities. The more spouses believed in a cure for HD the less they focused on and vented their emotions as a way of coping with the disease. The way in which spouses of patients with HD perceive HD seems not to influence their own quality of life.

Authors / Year	Objectives	Participants	Design & Measures	Relevant findings
Barrowclough et al, (2001)	To examine the illness representations of in carers of *schizophrenia patients*	47 carers of schizophrenia *patients* 68% female Mean age = 36.8 years	Cross-sectional Modified IPQ GHQ BDI (Beck Depression Inventory) SBAS (Social Behaviour Assessment Scale) GAS (Global assessment scale) PANNS (Positive and negative syndrome scale)	Greater perceived negative consequences for the patient was associated with a higher psychological *morbidity in the carer. Perceived* negative consequences was also consistently associated with adverse carer outcomes including higher psychopathology, depression and subjective burden. Problems relating to the symptoms of schizophrenia were associated with higher scores for carer distress. The chronic time-line and the *identity-symptom scores were associated with* patients' illness characteristics. For example, a longer time-line was associated with a longer duration of patient illness, a higher PANSS score, and lower scores on the GAS (indicating less adaptive functioning) and the social functioning scale. The findings demonstrate that links exist between illness representations and assessments of carer and patient outcomes. The well-being of carers was mainly related to perceptions of the magnitude of the consequences of the illness for themselves.

Authors / Year	Objectives	Participants	Design & Measures	Relevant findings
Roberts & Connell, (2000)	To examine the illness beliefs and experiences and risk of developing Alzheimer disease.	203 First-degree relatives of people with Alzheimer disease Mean age = 53.5 years	Cross-sectional Illness representations measure based on IPQ dimensions	With regard to cause, participants rated genetic factors as the most important cause of Alzheimer's. However, 34% of participants endorsed beliefs in potential environmental factors such as diet/lifestyle and mental inactivity as a possible cause suggesting some belief in personal control over the onset of Alzheimer's. The distress experienced through having a relative with Alzheimer's manifested itself in the form of 'intrusive thoughts', 'intense emotions' and 'intrusive imagery' and a quarter reported sleep difficulties. More than 75% of participants reported that both the emotional and financial consequences of developing Alzheimer's would be at least very stressful, with a quarter of respondents anticipating such an outcome would be overwhelmingly stressful for them and their families.
McClenahan & Weinman, (1998)	To determine the extent of carer distress in non-acute stroke	86 carers of people with non-acute stroke	Cross-sectional Adapted IPQ GHQ (General Health Questionnaire)	Only the time-line dimension of the IPQ was related to distress scores. The time-line variable was then entered into a regression analyses alongside other correlated constructs such as self-efficacy and coping variables. In total the independent variables explained 45% of the variance in distress experienced by carers.

2.15. Discussion

The findings of the studies reviewed in the second part of this chapter suggest that the study of illness representations of patients and significant others may be particularly fruitful for understanding how illness beliefs develop in the social context. In particular, the findings demonstrate how differences in the beliefs of significant others and patients influence psychological adaptation to chronic disease (Heijmans et al, 1999; Figueiras & Weinman, 2003, Urquhart-Law, 2002) and behavioural outcome (Weinman et al, 2000, Figueras & Weinman, 2003). This limited evidence suggests that the illness representations and causal attributions of partners of chronically ill individuals are influential in adaptation to chronic illness. In addition, there are a number of studies that have solely examined the representations of carers, relatives and spouses' of individual's with chronic disease in relation to their own well-being rather than the their impact on the patient (Helder et al, 2002b, Roberts & Connell, 2000, McClenahan & Weinman, 1998).

Approaches in measuring the representations of significant others

The studies reviewed here have, largely, adapted the original Illness Perception Questionnaire as a means of measuring the illness representations of significant others (Heijmans et al, 1999, Figueiras & Weinman, 2003, Helder et al, 2002b, McClenahan & Weinman, 1998, Barrowclough et al, 2001). In general, studies utilising this approach have used a re-worded version of the measure to elicit the partners perceptions of the patients illness. Support for the validity of this approach to assess the representations of significant others is provided by the reporting of generally comparable internal reliability coefficients (Heijmans et al, 1999, Figueiras & Weinman, 2003, Barrowclough et al, 2001, Helder et al, 2002b). To date, only one study has utilised the revised version of the IPQ in this regard (Urquhart-Law, 2002). However, this study has shown the importance of differences in the new scales *illness coherence* and *emotional representations* between adolescents with type 1 diabetes and their mothers.

A further issue arising from this review is with regard to Barrowclough et al's (2001) study and the extent that a patient is to blame for the onset or exacerbation of a disease is perceived by the partner. As Leventhal et al. (1984) suggest that the importance of different aspects of the representation will vary depending on the nature of the illness. An important omission in the IPQ in this context is beliefs about how 'blameworthy' the patient is for failing to exert more control over his/her symptoms. Indeed, attributions of *control* measured in the modified IPQ explore general beliefs about the carers' perceptions of the amenability of the illness to be controlled rather than specific 'patient blame'. Clearly, perceptions of blame have implications for physical disease with aetiology relating to a patients' lifestyle such as diabetes or CHD.

Representations of significant others and outcomes in chronic disease

The studies conducted assessing the illness representations of significant other have generally looked at issues relating to patients' adaptation to disease such as coping, physical and social functioning, quality of life (Heijmans et al, 1999, Helder et al, 2002b, Figueiras & Weinman, 2003) and well-being (Urquhart-Law, 2002). The assessment of behavioural adaptation to a diagnosis of chronic disease may be particularly pertinent as health behaviours may be viewed as a coping response that is influenced by the illness representations of significant others. To date only two studies have examined the relationship between representations of significant others and health behaviours (Weinman et al, 2000, Figueiras & Weinman, 2003). However, these studies demonstrated that the representations of significant others play an important role in recovery from MI and therefore may be important in other 'lifestyle' diseases such as diabetes.

Directions for future research

The findings of the reviewed studies demonstrates that the assessment of illness representations of significant others provides a useful insight into the influence of

a patients' social context on disease. That said, the studies examining the representations of significant others are few and share little commonality with regard to methodology. Therefore, there is a need for the further examination of the interaction of dyadic representations if the phenomenon is to be more clearly understood. This raises a number of issues that need to be addressed in future work in this context.

First, there is no consensus as to how 'dissimilarity' in patients' and partners' illness representations should be measured or how to utilise differences with regard to predicting patient or disease outcomes. Second, the lack of prospective studies examining the illness representations of significant others does little to delineate how illness representations of dyads develop in response to a diagnosis of disease. Therefore, longitudinal studies are required to delineate the magnitude of the influence of the spouse or partner with regard to adaptation to a diagnosis of chronic disease and relevant health behaviours. In addition, there is scope for studies to be conducted with individuals at risk of disease or before a diagnosis is given. For example the illness representations of individuals with insulin resistance and their partners could be assessed before the onset of symptoms. In response to some of the issues raised, the present thesis will examine the illness representations of patients; with type 2 diabetes patients and their partners' employing a prospective design.

CHAPTER 3: PROJECT STUDY

3.1. Introduction

The second chapter of this thesis examined the utility of the illness representations framework in predicting behavioural, psychological and clinical outcomes in chronic disease. Of particular relevance to the present thesis was the focus on adherence to treatment recommendations in chronic illness and the extent that illness representations play in predicting such behaviour.

This chapter introduces the research project conducted for the present thesis. The project is an investigation into the role of 'significant others' in determining the health behaviours of patients with type 2 diabetes. The chapter will provide information regarding ethical approval, the recruitment of participants and the study procedure. The rationale for the selection of both explanatory and outcome measures is also described.

3.2. Self-management and the social context

Many factors can directly and indirectly influence disease management behaviour and metabolic control of people with diabetes. In addition to individual variables (biological and psychological factors), it is evident from the literature reviewed in Chapter 1 that patients' health behaviours and subsequent glucose control is influenced by transactions within the context of the family and the broader social and cultural community. It is the influence of the immediate social environment on self-management behaviour, namely 'significant others' (defined as the patient's spouse or partner), that is the focus of the project.

3.3. The role of illness representations

A substantial body of quantitative investigations support an association between the five dimensions of illness representation described by Leventhal and a range of psychological and behavioural and clinical outcomes (Chapter 2). For example,

illness representations have been found to be related to coping (Heijmans, 1998, 1999; Moss-Morris et al., 1996; Scharloo et al., 1998, 2000a, b), psychological morbidity (Fortune et al, 2000, Murphy et al, 1999), functional adaptation or adjustment to illness (Heijmans ,1998; Heijmans et al, 1999; Petrie et al., 1996; Scharloo et al, 1998) and also adherence to a range of medical recommendations (Cooper et al, 1999; Weinman et al, 2000). Additional investigations using the Personal Models of Diabetes Interview (PMDI) demonstrated the applicability and validity of representations of diabetes. This work has shown that the illness representations of diabetic patients were related to their self-reports of dietary intake as well as levels of physical activity (Hampson et al, 1990, 1995, Glasgow et al, 1997).

At present, the application of the illness representations framework in chronic disease is limited with regard to the role of 'significant others' in the health behaviours of patients. However, it was demonstrated that the beliefs partners/carers hold in relation to a patients' illness are important in patients' adjustment to their illness, their well-being and subsequent health related behaviours (Heijmans et al, 1999, Weinman et al , 2000, Figueiras & Weinman, 2003). The focus of the present thesis is to determine the role of significant others in the health behaviours of patients with type 2 diabetes. It is, therefore, necessary to examine how patients' beliefs and attitudes regarding the uptake and maintenance of health behaviours are influenced by the social milieu of the patient. It is proposed that in addition to examining the health beliefs of the patient, it may be equally important to examine the health beliefs of the partner. It is postulated that the extent and type of social support received by patients may be moderated by the extent that partners' and patients' illness beliefs converge. For example, a partner of a patient with diabetes may perceive the illness as having less severe *consequences* and that the treatment was less effective for controlling diabetes than the patient. It is argued that such representations would not favour adherent behaviour by the patient, particularly if these representations determine the level of support the patient receives from the partner. This endeavour will serve to further inform the role of the social context in the management of diabetes. Specifically, it will assist in delineating if the health beliefs of 'significant others'

play an active role with regard to the patients' health behaviours. Whether beliefs are shared or are different it is important to explore the magnitude such beliefs have on patients' health behaviours.

3.4. Aims of study

The primary aims of the study were to examine the effectiveness and validity of the illness representations framework in predicting behavioural, psychological and clinical outcomes in patients with type 2 diabetes.
In particular, the study aims to;

- Assess the illness representations of patients with type 2 diabetes and their spouse or partner.
- Determine if the illness representations of patients and partners differ with regard to living with diabetes.
- Examine the extent to which the representations of the patient and partner are associated with the patient's self-management of diabetes.

3.5. Ethical approval

Ethical approval for the study was granted by the South and West Multi-centre Research Ethics Committee in Spring 2001. As participants were recruited from primary care surgeries participating in the Somerset and Avon Survey of Health (SASH) Diabetes Study it was also necessary to obtain approval from the 5 local ethical committees representing the areas involved (United Bristol Health Care Trust, North Bristol NHS Trust (Southmead and Frenchay), Weston and West Somerset (Taunton).

3.6. Study design and methods

The primary research aims were addressed via quantitative methodology through the administration of self-report questionnaires. The study adopted a prospective

design with 2 phases of data collection, 0 months (baseline) and 12 months. All phases of data collection were undertaken by posting the questionnaires to the participant's home address. All measures assessing the participant's adherence (self-management behaviour) to diet, physical activity and medication were assessed through self-report questionnaires.

3.7. Participants

Somerset and Avon Survey of Health

The study participants were derived from a cohort of 28,080 individuals aged 35 or over who were originally enrolled in the Somerset and Avon Survey of Health (SASH) in 1993 to 1995. In brief, this cohort was obtained by sampling a fixed number of patients from 40 primary care surgeries. The surgeries were taken from a mix of rural, suburban and inner city locations. A total of 1068 patients with either type 1 or type 2 diabetes were identified from this cohort. However, General Practitioners were asked to exclude anyone who had a severe mental illness, terminal illness or who had changed address or died. This procedure resulted in 789 diabetes patients that were approached to participate in the 'SASH Diabetes Study'. A total of 586 patients consented to participate in the study giving a response rate of 79%. A total of 19 patients were omitted from the recruitment procedure as these individuals claimed not to have diabetes.

Recruitment of type 2 diabetes patients from SASH Diabetes Study

In order to recruit patients for the present study participants with type 2 diabetes from the 'SASH Diabetes Study' were identified. Patients were classified as having type 2 diabetes if they were either:

1. treated by diet only
2. treated with oral drugs (no insulin)
3. treated with insulin (age of onset > = 35)

Of the 567 patients in the original 'SASH Diabetes Study' a total of 506 patients were classified as having type 2 diabetes.

In order to contact these patients, the practice managers of the 40 primary care surgeries on the SASH database were contacted by telephone and, if agreeable, were sent details on the proposed project to be given to the relevant GP. The GPs were requested to give their approval to contact diabetic patients under their care that met the following inclusion criteria:

1. the patient had a diagnosis of type 2 diabetes
2. the patient was married and or living with a partner.

The GPs were also requested to verify the patients' diagnosis and notify the author of any changes of address, physical health and whether the patient was still under their care (either deceased or left the practice). Furthermore, any dyads in which both patient and spouse had diabetes were excluded. Once approval from the GP was given, eligible patients were contacted directly by the author as consent had been given by their participation in previous studies relating to SASH.

Recruitment of patients from Bristol Primary Care Research and Development Consortium

In an attempt to increase the number of patient-partner dyads in the study the Bristol Primary Care Research and Development Consortium (BPCRDC) were approached. This procedure led to the identification of 12 contactable GP surgeries. Patients attending these surgeries had no prior experience of the 'SASH Diabetes Study', therefore for reasons of patient confidentiality and in accordance with the recommendations of the Caldicott agreement (Caldicott Committee, 1997) the initial approach to recruit these patients came from the relevant GP. Thus, study invitation letters were sent to these patients printed on relevant GP surgery letter-headings (see Appendix 2.). These invitation letters described the nature of the study and contained a reply slip and pre-paid envelope for patients to return if they were interested in receiving more details regarding the study.

Participants

A total of 29 surgeries from SASH and gave consent to contact eligible patients and 6 surgeries representing the BPCRDC agreed to contact eligible patients. In addition to this, the Diabetes Unit at Southmead Hospital, Bristol agreed to recruit patients attending diabetes education classes. In October, 2001 a total of 225 patients meeting the study inclusion criteria (i.e., had a type 2 diagnosis and living with partner) were sent a 'study pack' containing an invitation letter (Appendix 3.), an information sheet (Appendix 4.), consent forms for patient (Appendix 5.) and partner (Appendix 6.), a questionnaire booklet (for patient and partner) and a FREEPOST envelope to return completed questionnaires. Patients were sent a postal reminder at 3 weeks and patients who had not returned questionnaires at 6 weeks received a telephone reminder (Appendix 7).

Of the 225 patients from the SASH cohort 95 heterosexual patient-partner dyads consented to participate (42% response rate). However, on return of study booklets it was revealed that 12 partners of patients had either not completed the relevant questionnaires adequately. These patients were omitted from the study leaving n= 83 dyads.

A further 150 patients with type 2 diabetes with no previous involvement in SASH were approached through primary care surgeries participating in SASH and from the practices representing the Bristol Primary Care Research and Development Consortium. In line with current research governance guidelines it was necessary for relevant GPs to invite eligible patients to participate in the study before consent was obtained. This procedure resulted in the recruitment of a further 89 participants (59% response rate). Of these there were 8 partners of patients who failed to complete their questionnaires and were omitted from the study.

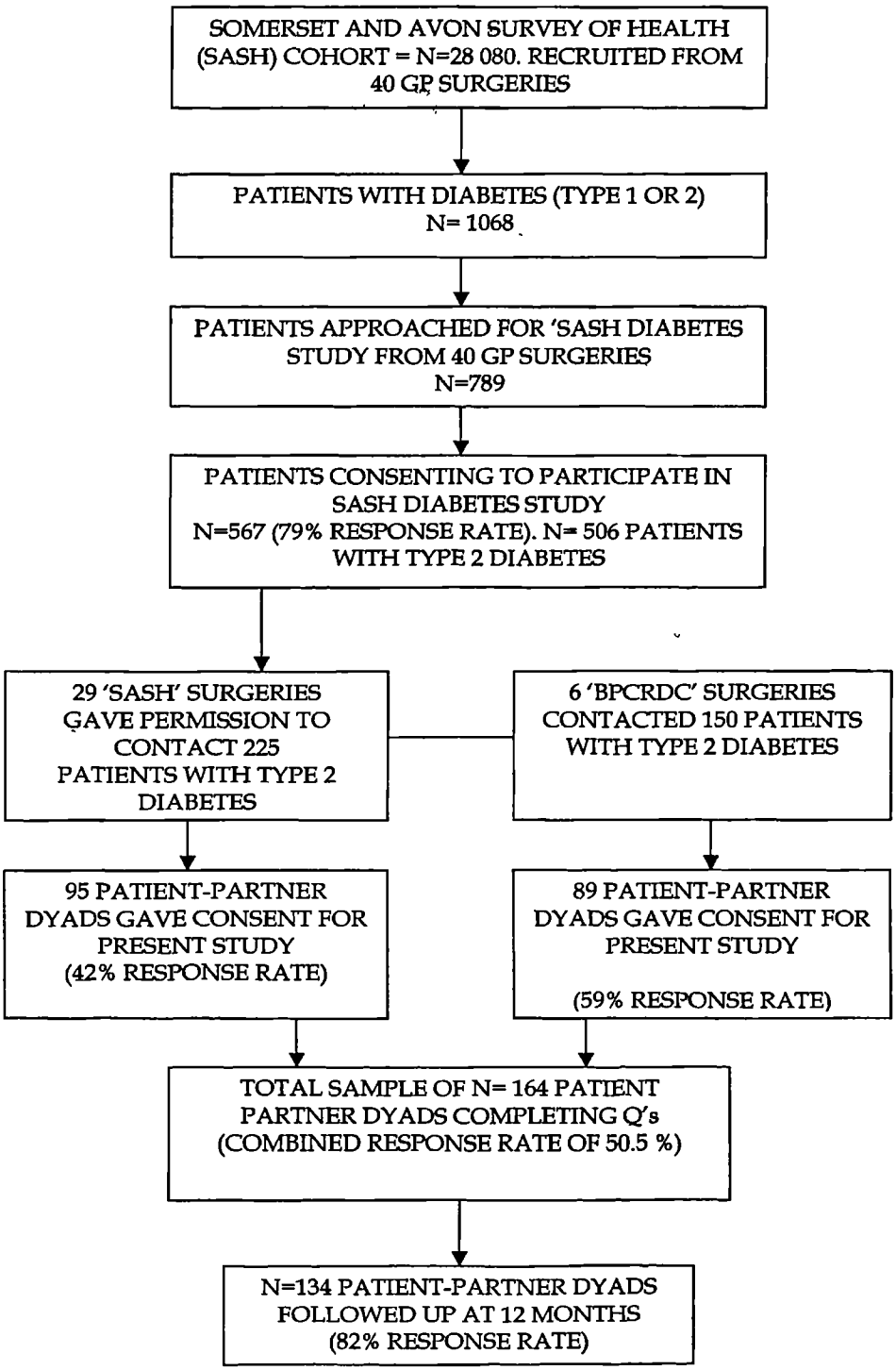
The combination of the two recruitment procedures yielded a final sample of n=164 dyads (50.5% response rate). Independent t-tests were conducted to determine if the demographic (age, gender, years married, ethnicity) and clinical (disease duration, BMI, weight, medication) characteristics of the patients recruited

through the two procedures were significantly different. This analysis revealed that patients who had not previously participated in the 'SASH diabetes study' had been diagnosed with type 2 diabetes more recently ($t = 2.72$, $p < .01$). Further independent t-tests were conducted to determine if the final patient sample (n=164) differed significantly from patients with type 2 diabetes participating in the 'SASH Diabetes Study'. No significant differences were found for age, gender and ethnicity and a range of co-morbid conditions with the exception of hypertension ($t = -3.43$, $p < .001$). Thus, patients in the present sample reported less hypertension than patients participating in the SASH Diabetes study. The recruitment procedure is illustrated in Figure 3.1.

Follow-up

After a period of 12–14 months all patient-partner dyads were contacting again to complete the follow-up phase of the study. The questionnaire booklets were sent again via post (containing same scales) to patients responding in the first phase of data collection. At three weeks, patients not returning questionnaire booklets were sent reminder letters followed with a telephone reminder at 6 weeks. The final sample at follow-up was n=134 dyads, giving a response rate of 82%.

Figure 3.1 Flow diagram of recruitment procedure.



Socio-economic and clinical data

A series of questions assessing the sociodemographic profile and health status of the participants were included in the questionnaire. These items asked patients and partners to state their ethnic background, current and former occupation (as applicable) and educational status.

To assess the extent of co-morbidity affecting patients they were asked to indicate which conditions from a list of 18 they had suffered within the preceding 12 months. The patients were also asked to state if they were prescribed insulin, and if they were prescribed any additional medicine as part of their treatment regimen for type 2 diabetes. Finally, patients were asked to state what type of diabetes they had (i.e., type 1 or type 2.).

Demographic data

The mean age of the participants was 67 years, the mean age for partners was also 67 years. The majority of patients (54%) were in retirement or approaching retirement age. Patients and partners who were still in paid employment were likely to have semi-skilled or manual occupations. The majority of patients and partners had left school before the age of 16. The number of years married or living together ranged from 2 to 64 years, indicating that all the participants were in well established relationships. Finally, despite recruiting patients from primary care practices in geographically diverse areas, only 5% of participants were from non-European ethnic groups.

Co-morbidity

The incidence of co-morbidity in the study sample was common, many patients reported suffering from other serious chronic conditions within 12 months before study entry. The most common conditions were Hypertension (43%) and arthritis (31%). Other conditions included angina (12%), asthma (11%), other heart trouble (9%), MI (6%), stroke (6%) and cancer (6%).

Table 3.1. Demographic data for sample population (n=164)

	Patient	Partner
Age	32– 86 years Mean= 67 years	33-87 years Mean= 67 years
Gender	Male: n= 97 Female: n= 67	
Ethnicity	95% White European	97% White European
Disease duration	6 months - 38 years Mean = 8.8 (7.07) years	
Years married/ living together	2 - 64 years Mean= 35.6 (14.7) years	
Occupation	54% retired 10% professional 32% semi-skilled manual 4% unemployed	47% retired 5% professional 38% semi-skilled manual 10% unemployed
School leaving age	14 years = 28% 15 years = 32% 16 years = 25% Other age = 15%	14 years = 24% 15 years = 37% 16 years = 24% Other age = 15%
Co-morbidity (in last 12 months)	Arthritis = 31% Asthma = 11% Nervous disorders = 11% Angina = 12% MI = 6% Hypertension= 43% Other heart trouble = 9% Stroke = 6% Cancer = 6%	

3.8. Measures

Illness representations

The illness representations of participating patients were assessed with the Revised Illness Perception Questionnaire (IPQ-R: Moss-Morris et al., 2002). The development of this measure was described in detail in Chapter 2. The measure has been psychometrically evaluated in 711 patients from 8 different illness groups including patients with diabetes. The IPQ-R encompasses 38 items within sub-scales reflecting the 'core 'dimensions of the illness representations framework (i.e., *time-line, consequences, control, identity,* and *cause*) and includes three new related concepts. The new sub-scales are; (1) *emotional representations* (to assess emotional responses such as fear, anxiety and anger generated by the illness), (2) *illness coherence* (to assess how the illness "makes sense" to the patient) and (3) *time-line cyclical* (to assess day to day variability in symptoms of the illness). Finally, the

control dimension of the IPQ-R now assesses *personal control* and *treatment control* with two separate sub-scales.

The IPQ-R was specifically adapted for use in the present diabetic population. Typically, this was achieved by replacing the word 'illness' with 'diabetes' for all applicable items. One item (item 20 of IPQ-R; 'My treatment will be effective in curing my illness') was changed to read 'My treatment will be effective in managing my illness) in recognition of the fact that there is no cure for diabetes. Finally, a further item was added to the *treatment control* sub-scale (i.e., 'My diabetes can be controlled by my treatment') making 6 items in total for this sub-scale. All items were rated on a 5-point scale (1= strongly disagree to 5= strongly agree). In order to avoid 'response set' bias in the participants, the items were randomly presented in the diabetes-specific version of the IPQ-R. This measure can be seen in full in Appendix 8.

Consequences

The *consequences* dimension is a measure of the perceived impact the illness has on a patients' life . It is assessed with 6 items (α= 0.84) and scored on a 5-point scale; 1= strongly disagree to 5= strongly agree (e.g., 'My illness has major consequences on my life').

Time-line

The *time-line* dimension is a measure of the perceived course or duration of the illness and provides an indication of the extent that the patient perceives the illness as an acute versus a chronic state. It is assessed with three items (α=0.89) (e.g., 'I expect to have this illness for the rest of my life').

Time-line cyclical

The cyclical *time-line* sub-scale measures the extent of illness variability and unpredictability. For example, the perceived experience of the illness may fluctuate according to the degree of control of diabetes. The sub-scale is comprised

of 4 items with a reliability alpha of α =0.79 (e.g., 'My symptoms come and go in cycles').

Control

The revised *control* dimension now measures the patients' perceived control of illness in two distinct sub-scales. First, *treatment control* (treatment efficacy) measures the patients' belief that treatment is effective in controlling the illness and is assessed with 5 items (α= 0.80) (e.g., 'My treatment will be effective in controlling my illness'). The *personal control* sub-scale measures the patients' perceived efficacy in controlling their illness and is assessed with 6 items (α= 0.81) ('There is a lot that I can do to control my illness').

Emotional representations

Items for the *emotional representation* sub-scale measures perceived emotional states such as anger, fear, anxiety and depression that a patient may associate with the illness. It is assessed with 6 items (α=0.88) (e.g., My illness makes me feel angry'). A higher score on this scale is indicative of a greater emotional impact of the condition.

Illness coherence

The *illness coherence* dimension is a 5-item measure of the extent to which a patient's illness representations are collectively helpful in providing a coherent understanding of the illness and is described as a 'meta-cognition' (Moss-Morris et al, 2002). A higher score on this sub-scale is indicative of an increased awareness of the illness and the degree to which it makes sense to the patient in terms of the perceived cause, control, consequences, and course (α= 0.87; e.g., 'I have a clear understanding of my illness').

Cause

Weinman et al (1996) suggest that the items of the cause sub-scale should be modified according to the illness being investigated. Therefore, patients' representations of the *cause* of their diabetes was assessed with a list of 13 possible causes for their diabetes. Therefore 10 items were taken from the IPQ-R (i.e., 'stress or worry', 'hereditary', 'germ or virus', 'diet or eating habits', 'chance or bad luck', 'poor medical care in past', 'my own behaviour', 'pollution', 'smoking' and alcohol). Three other items were added by the author (i.e., 'lack of exercise, my weight, and other people).

The participants were asked to rate on a 5-point scale (1= strongly disagree to 5= strongly agree) the extent to which they felt that each factor had caused their diabetes.

Personal models of diabetes

In conjunction with items from the IPQ-R, sub-scales from the Personal Models of Diabetes Interview were included. These scales have been shown to be important predictors of the health behaviours of patients with diabetes (Hampson et al, 1990; 1995). First, to make the measure more diabetes-specific, a list of 10 symptoms associated with high blood glucose and 11 symptoms associated with low blood glucose replaced the 14 general illness symptoms included in the original IPQ-R *identity* sub-scale. The participants were instructed to tick either 'Yes' or 'No' as applicable to indicate their experience of each symptom.

In addition, the *control/cure* dimension of the illness representations framework (IPQ-R) was expanded to include 13 items to assess the relative importance of specific aspects of diabetes *treatment* for controlling diabetes *now* and for avoiding complications in the *future*. For example, participants were asked to rate on a 5-point scale (1= not important to 5= very important) how important it is to exercise regularly, eat a diet low in fat and high in fibre and to take one's medication for controlling diabetes now. The same questions were asked again but this time the emphasis was on the perceived importance of these behaviours for avoiding future complications of diabetes.

Illness representations of the partner

A 'significant other' version of this measure was also produced to be completed by the spouse / partner of patients with diabetes. All the items of the measure devised for the diabetic patient were rephrased to assess the partner's representations of the patient's diabetes. For example, the item; 'My diabetes will improve in time' was modified to read; 'My partners' diabetes will improve in time, and 'I have a clear understanding of my diabetes' was modified to read 'My partner has a clear understanding of his/her diabetes'. This measure can be seen in full in Appendix 9.

Outcome measures

As described earlier in Chapter 1, type 2 diabetes is primarily managed with diet, regular physical activity and medication. Therefore, the extent of adherence to these behaviours were chosen as the primary determinants of self-management in the present study. From the literature reviewed in Chapter 2 it is evident that many previous studies have relied on a single measure to assess self-management behaviours in diabetes such as diet, physical activity and medication adherence, namely the Summary of Diabetes Self-care Scale. For the present study it was considered that an improvement could be made by employing behaviour-specific measures to assess patients' adherence to these behaviours. Therefore relevant scales were included to assess the three key behavioural outcomes in the study; diet, physical activity and medication.

In addition to these behavioural outcomes, psychological morbidity was assessed as it is proposed these 'psychological' outcomes may be 'markers' for the patients' adaptation to diabetes. Finally, as the family environment was shown to be particularly important in patient's management and control of diabetes in Chapter 1, the measurement of marital satisfaction in patients and partners was included in the study.

Diet

It is likely that the responsibility for healthy eating habits lies not only with the diabetic patient but also with their spouse or partner or others sharing the same household. It is, therefore, suggested that it is important to examine the social context of eating behaviour, particularly, within a shared household (i.e., cohabiting couples).

Previous studies examining psychological variables and adherence to a diabetic regimen have not adequately assessed dietary adherence. For example, studies have tended to rely on 'self-care' inventories where the respondent is asked general questions about their dietary behaviour in addition to other aspects of the regimen such as levels of exercise, medication adherence, glucose testing etc. It was thus deemed necessary to assess the quality and quantity of the typical weekly diet of the diabetic patient and this was achieved with a Food Frequency Questionnaire

Food Frequency Questionnaire

The Food Frequency Questionnaire selected was originally developed by the Health Education Authority (HEA 3, Little et al., 1999; 2000). This measure was primarily developed as a simple self-report dietary assessment tool in the context of primary care particularly for providing counselling for patients at risk of cardiovascular disease. The measure has been shown to perform as well as more time consuming methods and almost as well as the accepted standard reference, a seven-day weighed record (Little et al., 2000).

Respondents were asked to indicate how often, on average, they have eaten a range of foods over the past month. The HEA 3 categorises individual food items into the following groups (i.e., bread/cereal/ potatoes; fruit/vegetables; meat/alternatives; cakes/puddings; sugar; drinks; fats; milk and dairy products. Respondents were requested to indicate their average portion size (i.e., small, medium, large; an example of a medium serving is given) for each item on the list.

The respondents are also asked to state how often they consume each item (i.e., day, week, month). This measure can be seen in Appendix 10.

Additional questions were asked to assess whether the respondents used wholemeal bread, high-fibre breakfast cereal, wholegrain rice, low-fat dairy products and what type of fat was used for spreading/frying etc.

Using responses to this questionnaire a computer programme was developed in association with a Public Health nutritionist. The programme used standard portion size data and nutritional data to calculate the energy intake for each respondent consumed as fat, saturated fat, sucrose, fibre, carbohydrate, fruit and vegetables and starch over a typical month.

Weight and weight management

In addition questions were asked regarding weight control (i.e., Have you been recommended to lose weight by your GP?; 'Are you currently dieting to lose weight?'. Participants were asked to report their current weight and height in order to calculate their body mass index (BMI).

Physical activity

The effectiveness of exercise in the management of type 2 diabetes is well established. Improvements in glucose homeostasis, cardiovascular risk and quality of life have been reported after moderate and vigorous exercise (Lehman et al, 1995; Mayer-Davis et al, 1998; Walker et al, 1998; Ligtenberg et al, 1998). However, despite numerous studies supporting the benefits of frequent physical activity for people with type 2 diabetes, an estimated 60-80% of this population remain sedentary (Ford & Herman, 1995; Hays & Clark, 1999).

To assess levels of intentional physical activity (other than exercise in the course of occupational activity), two sub-scales from the Baecke habitual physical activity questionnaire (Baecke et al., 1982) were used (see Appendix 11). First, the 'sports index' is concerned with the extent and intensity of a particular activity such as

cycling, walking etc. This scale asks respondents to state their most frequently played sport and indicate how many hours per week and how many months per year he/ she engages in the sport. The respondent is also asked to state a second sport and to rate it in the same way. The 'sports index' also comprises of a further 3 items concerned with the level of physical activity (e.g., 'In comparison with others my own age, I think my physical activity during leisure time is 1=much more, 2=more, 3=the same, 4= less, 5= much less').

The 'non-sports index' is concerned with exercise taken in going about everyday life such as walking to shops etc and comprises of 4 items. For example, respondents are asked to rate their extent of agreement or disagreement to statements such as; 'During leisure time I watch TV'; 1= never, 2= seldom, 3= sometimes, 4= often, 5= very often). The mean scores for the two scales are summed to provide a composite measure of physical activity. The 'non-sports index' scale has good test-retest reliability at 3 months with a Pearson correlation of 0. 74. Overall, the measure has been shown to have high reliability and provides an accurate assessment of both heavy intensity exercise as well as light intensity activities which in turn has been associated with measures of aerobic fitness and body fatness in expected directions (Richardson et al., 1995).

Medication

Many patients with type 2 diabetes are required to take oral medication in addition to careful adherence to diet and exercise to control blood glucose. The sulfonylurea class of drugs play a primary role in the pharmacological management of type 2 diabetes (Florence & Yeager, 1999). Metformin is another oral agent that is frequently prescribed to lower blood glucose and may be used in combination with sulfonylureas and other agents. Patients with type 2 diabetes become less responsive over time to one agent alone and frequently require combination therapy to adequately control their disease.

The extent of the patients' adherence to such agents was assessed with the Medication Adherence Report Scale (MARS; Horne, 2001). The MARS is a

validated 6-item scale that assesses the frequency of medication lapses in the previous 7 days (see Appendix 12.). It has also been designed to limit under-reporting of medication lapses by pre-empting patient's responses with a statement indicating that medication lapses are commonplace. The respondent is asked to rate their extent of agreement or disagreement to each statement on a 5-point scale (e.g., 'I avoid using my medicines if I can', 1= always true, 2= often true, 3= sometimes true, 4= rarely true, 5= never true.

Psychological morbidity

Having diabetes is associated with higher levels of depression than in the non-diabetic population. Indeed, a meta-analysis of 42 studies found that having diabetes doubles the odds of having depression (Anderson et al, 2001). Depression has also been implicated as a factor affecting good glucose control (Lustman et al., 1986). High levels of anxiety are also prevalent in patients with diabetes. A systematic review found elevated symptoms of anxiety in 40% of patients with diabetes (Grigsby et al, 2002).

To assess psychological morbidity in both patients and partners the Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983) was employed (see Appendix 13). A study using the HADS examining the prevalence of psychological morbidity in diabetes patients demonstrated that 28% of study participants reported moderate-severe levels of depression or anxiety or both (Lloyd, Dyert & Barnett, 2000). A greater proportion of patients (25%) reported these levels of anxiety than depression (8%). The HADS consists of two sub-scales each with 7-items measuring depression and anxiety. Since the HADS does not contain any items that measure somatic symptomatology, symptoms of anxiety and depression cannot be confounded with the physical symptoms of poorly managed diabetes. Scores of 11 or higher on either or both of the sub-scales indicate moderate-severe symptomatology or clinically significant disorder. Scores of 8-10 on either sub-scale indicate mild levels of anxiety and depression. All items are measured on a scale of 1 to 4 indicating the extent to which they feel the item reflects how they have been feeling in the last week (e.g., 'I feel as if I am slowed

down'; 1= most of the time, 2= a lot of the time, 3= time to time, occasionally, 4= not at all).

Dyadic adjustment

A further finding pertinent to the proposed project is the importance of marital satisfaction or adjustment in patients' adherence to treatment regimens. Therefore, it was felt necessary to include a measure of marital satisfaction to be completed by both patients and their partners. The original Dyadic Adjustment Scale is a 32-item measure of satisfaction in an intimate relationship (DAS; Spanier, 1976). It has four sub-scales that measure marital satisfaction, cohesion, consensus, and affectional expression. A higher score indicates better marital quality. The measure also correlates highly with the widely used Locke-Wallace Marital Adjustment Test (Locke & Wallace, 1957).

As the 32-item version of the DAS was considered too long, it is argued that a shorter scale assessing dyadic adjustment would be more appropriate in the present context due to the number of other measures used in this study. Therefore, the 7-item version of the Dyadic Adjustment Scale (Sharpley & Rogers, 1984) was selected for this purpose (see Appendix 14.). Investigation of the construct validity among the short-form alternatives of the DAS by Hunsley et al (1995) demonstrated that this scale is a valid version of the DAS.

Respondents are asked to indicate the extent of agreement or disagreement between them and their partner for 6 items of the DAS (e.g., philosophy of life; 1= always agree, 2= almost always agree, 3= occasionally agree, 4= frequently disagree, 5= almost always disagree, 6= always disagree). For the remaining item respondents are asked to circle a number on a continuum of 0-6 which most represents the degree of happiness in their relationship (0= extremely unhappy, 1= fairly unhappy, 2= A little unhappy, 3= happy, 4= very happy, 5= extremely happy, 6= perfect.

Glycosylated Haemoglobin (HbA1c)

An amendment to the original study protocol for which ethical approval was obtained made it possible to obtain an objective measure of blood glucose control to coincide with the completion of the final questionnaire booklet. Metabolic control measured by HbA1c reflects patients' mean metabolic control over the 6-12 weeks preceding measurement and is part of the routine management of patients with diabetes and widely accepted as reliable and valid index of metabolic control (Nathan et al., 1984, Goldstein et al, 1985). Higher values indicate higher blood glucose levels and hence poorer metabolic control.

A letter was enclosed with the final questionnaire booklet requesting patients to provide a blood sample specifically to determine the extent of control of their diabetes for the study (see Appendix 15). Due to the wide geographical dispersion of the study participants in the Somerset and Avon Survey of Health the study sample was divided into two groups for the collection of HbA1c. Patients living in the vicinity of the Bristol Royal Infirmary and those living in the vicinity of Weston General Hospital attended the appropriate clinic (see Appendix 16 for consent form). A total of 102 patients consented to give blood for the measurement of HbA1c (62% of the original 164 patients recruited, 76% of patients at follow-up). Independent t-tests revealed that patients providing blood samples did not differ significantly with regard to demographic (age, gender, years married) and clinical variables (disease duration, medication use, BMI and weight).

3.9. Plan of analysis

The first aim of the thesis is to determine and describe the illness representations of patients and partners with type 2 diabetes. To achieve this aim it is necessary to sum the responses to the relevant scales and calculate the mean for each sub-scale in accordance with the directions of the authors of the IPQ-R (Moss-Morris et al, 2002). To examine the second aim of the thesis; to determine the extent of

differences between patients' and partners' illness representations, a series of paired t-tests will be performed. This procedure was adopted in previous studies examining differences in the illness representations of patients and partners (Heijmans et al, 1999); and adolescent s and mothers (Urquhart Law, 2002) and can therefore be considered as the precedent for examining differences between the representations of patients and significant others.

The overall aim of the study was to examine the extent that the illness representations of partners are influential in patients' self-management behaviours. Specifically the study is endeavouring to determine if partners' representations of diabetes impact on patients' behaviours over and above the influence of patients' representations. To date, there are no studies that have specifically addressed the extent how partner representations impact on patient outcomes which leaves analytical approaches in this regard to be determined post-hoc. It was thus anticipated that decisions regarding analysis to determine the influence of partners' representations would be dependent to some extent on the distribution of scores for the outcomes of interest.

Bivariate correlational analysis will be conducted to examine inter -relationships between the dimensions of diabetes representations and also examine their relationships with the outcome variables. If the outcome variables do not assume a 'normal' distribution independent t-tests will be conducted to determine if differences exist with regard to diabetes representations. Multivariate regression approaches will be employed to determine the magnitude of the predictive utility of the diabetes representations. This procedure will permit demographic and disease related variables to be controlled and will allow the strength of partners' representations in predicting patients' behaviours over and above the influence of patients' own representations to be determined.

In Chapter 4 the analysis of the time 1 data collection is described. However, this paragraph provides an outline of the decisions and justification for the employment of the chosen analytical methods. On the strength that scores on the outcome measures were not normally distributed a decision was made to split

outcome scores at the median or clinically relevant cut-offs where appropriate. To examine differences between diabetes representations a series of independent t-tests were conducted. To further explore these relationships with outcome variables, and to control for demographic and clinical variables and the relative influence of patient and partner representations, binary logistic regression was employed. However, there are limitations associated with split data and the employment of logistic regression analysis that are discussed alongside alternative strategies in the discussion (Chapter 6).

CHAPTER 4: RESULTS-TIME 1

4.1. Introduction

This chapter summarises the descriptive data relating to the measurement of illness representations in patients with diabetes and their partners as described in the study procedure in chapter 3. In particular, the internal reliability of the patients' and partners' illness representation scales are assessed and the formation of scales assessing causal attributions through factor analysis are described. The extent of adherence with the recommended behaviours relating to diet and weight management, medication and physical activity is also described. The chapter proceeds with an examination of the differences between patient' and partners diabetes representations. The statistical methods used to examine the associations between representations and behavioural, psychological and dyadic adjustment outcome variables are described, as are the results. Finally, the chapter ends with an interim summary of the results of time 1.

4.2. Descriptive data

The data from the questionnaires for the first phase of data collection were analysed. Individual items of the sub-scales of the IPQ-R were summed in line with the authors' recommendations (Moss-Morris et al, 2002). Where applicable item scores were reversed. In addition, a missing data count was conducted for individual items on the IPQ-R which identified a minimal proportion of missing values, ranging from 0.8% to 4.2%. It is suggested that if greater than 10% of data is missing for a respondent the measure in question should be deemed as missing (Bryman & Cramer, 1997). As the proportion of missing data did not exceed 10% it was considered appropriate to replace missing values for individual items with the mean derived for the composite scales.

Scale reliability

To determine the internal reliability of the scales Cronbach alpha coefficients were conducted for patients with type 2 diabetes and their partners (n=164). The reliability coefficients for some of the IPQ-R sub-scales were not as satisfactory as coefficients reported by Moss-Morris et al (2002). This was particularly true for the *time-line, time-line-cyclical, consequences, personal control, treatment control* sub-scales although for patients the alpha coefficients were all above 0.6. An attempt was made to improve the alpha coefficients of the scales by removing weakly correlated items. However it was not possible to improve the reliability of any single scale (for patients and partners) by more than 0.5. Therefore all of the scales include all of the original items. The mean scores and alpha coefficients are shown in Table 4.1.

Table 4.1. Descriptive statistics for illness representation scales (n=164 patient-partner dyads)

Illness Representation	Max score	Mean (SD) Patient	Mean (SD) Partner	Alpha Patient	Alpha Partner
Timeline-acute	30	23.2 (4.8)	23.7 (4.3)	.63	.73
Timeline-cyclical	15	11.1 (2.8)	10.8 (2.8)	.60	.66
Consequences	25	17.2 (3.8)	17.1 (3.6)	.61	.58
Personal control	30	23.4 (3.8)	23.1 (4.4)	.61	.54
Treatment control	30	22.9 (4.6)	23.5 (3.5)	.68	.63
Illness coherence	25	17.5 (4.6)	18.4 (4.3)	.85	.81
Emotional representations	25	12.1 (3.6)	12.6 (3.7)	.80	.81
Control-now	65	60.3 (5.0)	61.0 (4.3)	.84	.80
Control-future	65	60.9 (4.9)	61.9 (3.7)	.69	.77
Cause- own behaviour	30	14.4 (4.0)	14.2 (4.5)	.71	.69
Cause-external	30	12.7 (3.6)	12.6 (3.5)	.67	.68
Cause-hereditary	5	3.2 (1.3)	3.2 (1.2)	n/a	
Identity-high bg	10	3.16 (2.2)	3.25 (2.3)	n/a	
Identity-low bg	11	3.20 (2.3)	3.41 (2.4)	n/a	

Importance of treatment to control diabetes 'Now' and in the 'Future'

Two scales adapted from the PMDI regarding beliefs in the importance of *treatment* to control diabetes *now* and *treatment* to avoid complications in the *future* relating to diabetes were also analysed. The *Control-now* scale has 13 items which were summed yielding a mean of 60.3 (SD= 5.07) for patients and 61.04 (SD =4.31) for partners. The reliability coefficients for the scale were .84 and .80 for patients and partners respectively. Similarly, the scale reflecting beliefs in the treatment to avoid complications in the future, *Control-future*, yielded a mean of 60.9 (SD= 4.93)

for patients and 61.9 (3.70) for partners. The alpha coefficients were .69 for patients and .77 for partners. As the maximum score for these scales is 65, it is clear that both patients and partners have strong beliefs in the importance of the treatment regimen for controlling diabetes now and for avoiding complications in the future.

Representations of cause

The frequency with which patients and partners endorsed each of the 13 items relating to the possible cause of diabetes as either 'agree' or 'strongly agree' were calculated (Table 4.2). For patients the 5 most frequently endorsed causes were; stress (50.6%) hereditary factors (41.6%), weight (31.3%), diet (29.3% and chance 24 1%). For partners the 5 most frequently endorsed causes were hereditary factors (43.5%) weight (32%), diet (27.4%), stress (26.2% , lack of exercise 13.1% . Although there was a general level of agreement between patients and partners particularly for hereditary factors, diet and weight as causes of diabetes, it would appear that for patients perceived stress was particularly salient as a perceived *cause* of diabetes. However, there was a clear disparity in patients' and partners' attributions of stress. It is suggested that patients more readily attribute stress as a cause of their diabetes rather than factors related to their own behaviour.

Table 4.2. Percentage of cause items endorsed as agree or strongly agree' for patients and partners n=164

Cause item	Patient	Partner
Stress	50 6	26.2
Hereditary	41 6	43 5
Weight	31 3	32.0
Diet	29 3	27.4
Chance	24 1	22.6
Own behaviour	17 4	11 9
Lack of exercise	15 1	13.1
Smoking	9 0	13 1
Alcohol	7.8	10 1
Other people	6 6	6 0
Germ / Virus	4 2	2 4
Poor medical care	4 1	1 2
Pollution	1 6	6

Factor analysis of causal attributions

The 13 items pertaining to the perceived *cause* of diabetes for patients and partners were factor analysed using principal components analysis (PCA). For all analyses, eigenvalues above 1.1 were used as selection criteria in accordance with Moss-Morris et al (2002). Items with loadings of greater than 0.45 were interpreted as representing a particular factor.

For patients, varimax rotation produced three factors which explained 50.9% of the total variance (see Table 4.3). The first factor included smoking, alcohol, germ /virus, chance, poor medical care and pollution as causes of diabetes accounting for 22% of the variance. The second factor included weight, own behaviour, diet and lack of exercise as causes accounting for 18% of the variance. The third factor included stress, other people and hereditary factors accounting for the remaining 11% of the variance.

Table 4.3. Results of principal components analysis of patient causal attributions (n=164)

Item	Factor 1	Factor 2	Factor 3
Stress	.283	.134	**.611**
Other people	.489	-0.004	**.620**
Germ or virus	**.635**	-0.003	.253
Weight	0.060	**.749**	0.054
Alcohol	**.654**	.272	-0.099
Smoking	**.671**	.114	-0.033
Hereditary	-.371	-0.002	**.660**
Own behaviour	.129	**.774**	0.004
Diet	0.016	**.856**	-.105
Chance	**.397**	0.043	0.060
Poor medical care	**.686**	0.071	0.044
Pollution	**.706**	-0.0098	.110
Lack of exercise	.116	**.564**	.315
Variance explained	**22%**	**17%**	**10%**

Table 4.4 Results of principal component analysis of partners' causal attributions (n=164)

Item	Factor 1	Factor 2	Factor 3	Factor 4
Stress	0.048	-0.081	**.814**	-0.032
Other people	.114	.351	**.706**	.203
Germ or virus	0.015	**.591**	.435	-.111
Weight	**.705**	-0.009	.111	.218
Alcohol	**.645**	.168	0.094	-.348
Smoking	**.517**	.115	.352	-.367
Hereditary	.122	-0.082	0.850	**.822**
Own behaviour	**.792**	.129	0.072	-.106
Diet	**.814**	0.048	-0.062	.221
Chance	-0.21	**.728**	-0.057	-0.097
Poor medical care	.212	**.787**	.101	0.059
Pollution	.228	**.849**	0.064	-0.015
Lack of exercise	**.505**	.233	-0.001	.306
Variance explained	**22%**	**19%**	**12%**	**9%**

For partners, PCA produced a four-factor structure of causal representations explaining 62% of the total variance shown in Table 4.4. The first factor included weight, diet, lack of exercise, own behaviour, alcohol and smoking as causal factors accounting for 22% of the variance. This factor reflects health behaviours for which the patient has responsibility. The second factor identified germ /virus, chance, poor medical care and pollution as causal factors accounting for 19% of the variance. The third factor comprised of only two items; stress and other people accounting for 12% of the variance. Finally, hereditary factors emerged as a single item factor accounting for 9% of the variance. To operationalise patients' and partners' representations of the *cause* of diabetes an attempt was made to make more meaningful scales that would also permit differences between patients and their partners to be identified. Thus the construction of the scales were jointly informed by; 1) the results of the factor analysis and 2) to reflect a distinction between internal and external causes as described by Weinman et al (1996 . As the distinction between 'internal' and 'external' causes was most apparent in the partners' causal structure and explained a large proportion of the variance, the construction of the 'internal' and 'external' scales were based on these results. Therefore, for the *internal* scale 6 items deemed to be under the volitional control of the patient were summed (i.e., smoking, alcohol, weight, behaviour, diet and lack of exercise). This scale was labelled 'own behaviour' with an alpha of 0.71 for patients and 0.69 for partners. For the external scale, 7 items which could be

described as being beyond the control of the patient (i.e., chance, germ /virus, poor medical care, and pollution, stress other people and hereditary factors) and labelled *Cause-external* yielding an alpha of 0.54 for patients and 0.56 for partners. However, the removal of hereditary factors from this scale increased the alpha coefficient to 0.67 for patients and 0.68 for partners. Therefore, hereditary beliefs were utilised as a single item variable.

Inter-correlation of diabetes representations

Pearson's correlation coefficients were computed to test for inter-correlation between the patients' representations of diabetes and also for partners' representations. A correlation matrix was constructed (See Tables 4.5 for patients and 4.6 for partners). For example, logical correlations were found for patients perceiving a longer *time-line* (r = .247, p <.05) and a stronger illness *identity* (r = .348, p <.05) with perceived *consequences* of diabetes. Stronger correlations were found between perceived *emotional representations* and *consequences* (r = .489, p<.01) and between *emotional representations* and *time-line* (r = .408, p <.01). Indicating that the perceived seriousness of the diabetes was reflected in stronger emotional discord and, interestingly, partners' correlation coefficients for these representations were shown to be even stronger (r = .596 and .586, p <.01).

Table 4.5. Inter-correlations between partners' representations of diabetes (p <.05 (2 tailed), ** p <.01 (2 tailed)

Representation	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Timeline													
2. Timeline-cyclical	.123*												
3. Consequences	.247*	.278**											
4. Personal control	.478*	-.121*	.112*										
5. Treatment control	.525*	-.155**	.113	.533**									
6. Illness coherence	.535*	-.276**	.089	.448**	.455**								
7. Emotional reps	.123*	.408**	.489**	-.099	-.143**	-.236*							
8. Identity-high bg	-.095	.427**	.348**	-.097	-.053	-.070	-.386**						
9. Identity-low bg	-.029	.274**	.362**	.004	.116*	.052	.247**	.570**					
10. Control-now	-.085	.007	.060	-.031	.125*	.083	-.083	-.027	.011				
11. Control-future	-.092	.016	.043	-.006	.156*	.078	-.020	-.031	-.009	.801**			
12. Cause-Own behaviour	-002*	.151**	.088	.097	.035	.005	.074	.124*	-.061	-.143**	-.147**		
13. Cause-External	.223*	.186**	.129*	-.211**	-.226**	-.297**	.288**	.153**	.014	-.044	-.058	.336**	
14. Cause – Hereditary	.180*	-.099	-.002	.119*	.145*	.204**	.019	.053	.158**	.058	-.003	.006	-.059

Table 4.6. Inter-correlations between partners' representations of diabetes (* p <.05 (2 tailed), ** p <.01 , 2 tailed)

Representation	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Timeline													
2. Timeline-cyclical	.155*												
3. Consequences	.009	.413**											
4. Personal control	.502**	-.089	-.123										
5. Treatment control	.455**	-.104	.030	.545**									
6. Illness coherence	.601**	-.179*	.005	.486**	.551**								
7. Emotional reps	-.093	.596**	.586**	-.140	-.054	-.083							
8. Identity-high bg	-.083	-.042	.046	-.096	.012	-.105	-.089						
9. Identity-low bg	-.086	-.038	.044	-.104	-.020	-.085	.036	.590**					
10. Control-now	.185*	-.045	-.008	-.039	.105	.170*	-.025	.056	.051				
11. Control-future	.231**	-.053	-.026	-.016	.105	.088	.005	.120	.032	.828**			
12. Cause-Own behaviour	-.028	-.059	.048	.042	.049	-.043	-.032	.066	.059	-.090	-.051		
13. Cause-External	.249**	.194*	0.57	-.223**	-.158*	-.308	.103	.027	.107	-.119	-.132	.355**	
14. Cause – Hereditary	.170*	.103	.029	.048	.101	.190*	.097	-.130	-.037	-0.23	-.084	.107	-.061

Clinical variables, illness representations and psychological outcomes

As the two-stage recruitment procedure yielded a wide variation in disease duration (6 months to 38 years) it was necessary to test for differences in patients' and partners' illness representations in relation to how long they had been living with the disease. First, the duration of the diabetes diagnosis was dichotomised to represent 'newly-diagnosed' and 'chronically' diagnosed patients. A diagnosis was deemed to be 'new' if it did not exceed two years at the time of study entry (n=47) a diagnosis exceeding two years was therefore deemed to be chronic (n=113). Independent t-tests revealed that there were no significant differences for patients' and partners' illness representations in relation to whether they had a new or chronic diagnosis.

Additionally, a small number of patients were prescribed insulin (n=31) as part of their diabetes management regime therefore it was also necessary to consider if this aspect of the treatment influenced the illness representations of patients and their partners. However, independent t-tests only identified differences for one variable: patients on insulin reported a higher identity score when blood-glucose was low than patients not prescribed this treatment agent (t < -1.479, p <.1).

Body Mass Index

One of the dietary related treatment objectives recommended for patients with diabetes is to achieve or maintain a desirable Body Mass Index (BMI). The BMI is the ratio of a person's weight to height. It is used as an indicator of obesity and is graded thus:

Grade 1: 17-14 (healthy weight)

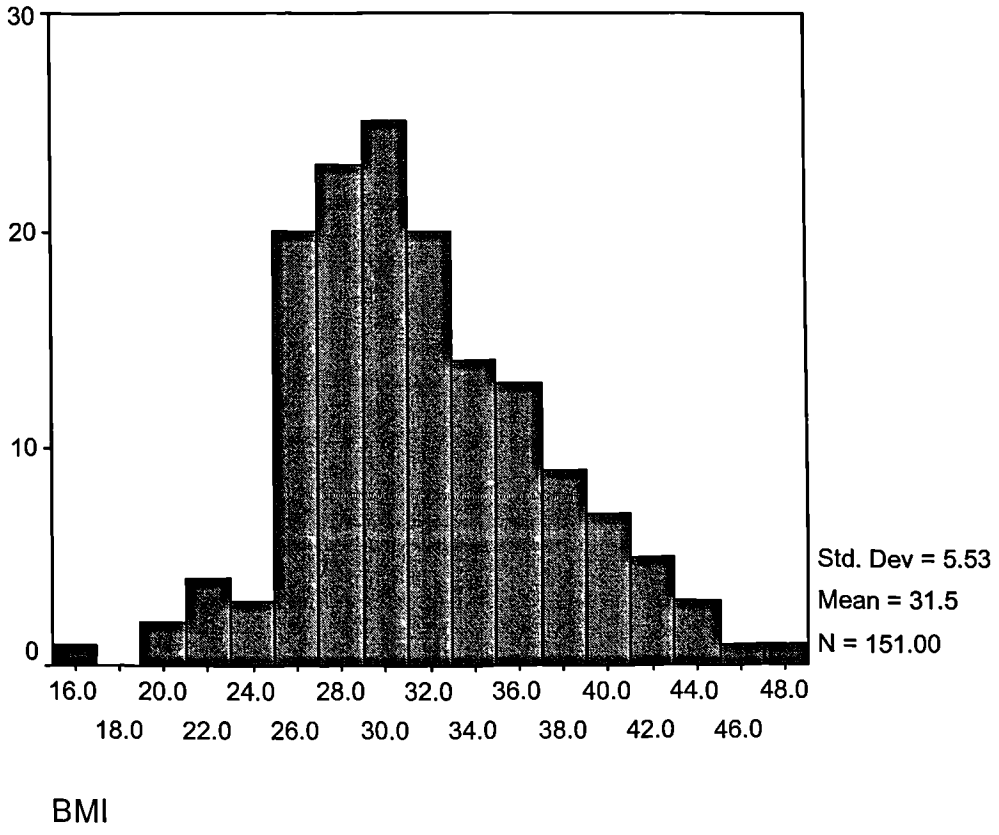
Grade 1: 16-37 (overweight)

Grade 3: 31-39 (very overweight)

Grade 3: >39 (extremely overweight)

A patient's BMI is calculated by dividing weight in pounds/kilograms by height in inches/centimetres ^{2}. The BMI was calculated for all patients reporting their current weight and height (n =151). Current body weight ranged between 51 and 160kg (mean = 91.8 kg (17.7), median = 88 kg. The mean BMI for the sample was 31.5 (5.53) and scores ranged from 16 to 48 with 90% scoring above the cut-off for being overweight of >25. The range of scores are shown in Figure 4.1. Therefore, it can be concluded that the present sample were predominantly overweight.

Figure 4.1. Distribution of patients' body mass index at time 1 (n=151).



Weight control

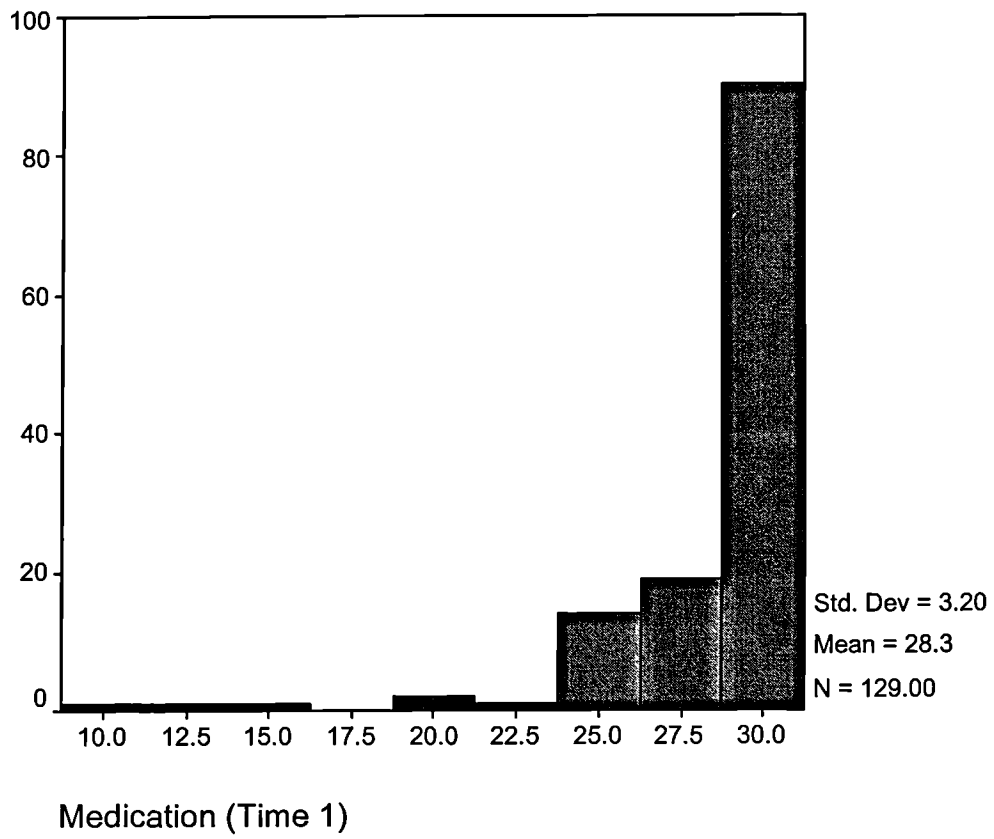
Data were also collected on weight control behaviour. Despite the prevalence of obesity within the sample, only 54% reported that they had been recommended to lose weight by their GP. Of these, 41% reported actively trying to lose weight at

entry to the study and 36% had made between 1 and 6 attempts at dieting to lose weight in the previous 12 months.

4.3. Measures of outcome; medication, physical activity, diet, psychological morbidity and dyadic adjustment

Medication

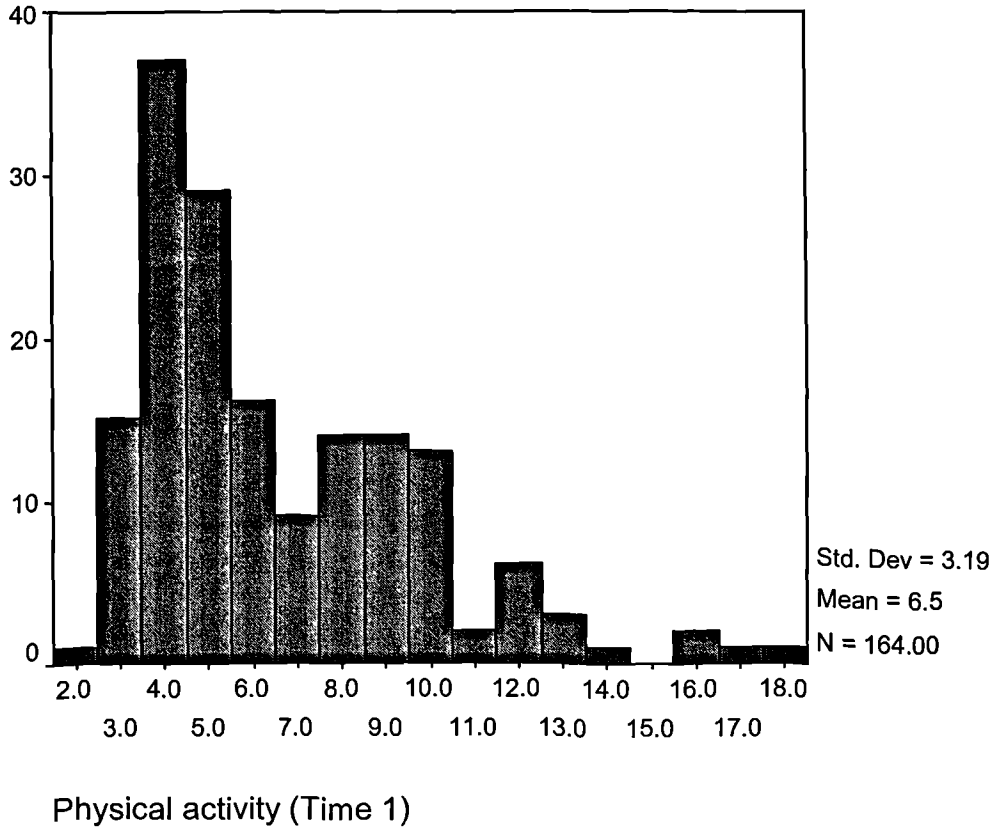
Figure 4.2. Distribution of scores for patients' scores on medication adherence report scale at time 1 (n=129).



Of all 164 patients, 129 patients reported taking oral medication such as Metformin and Gliclazide to control their diabetes and 37 patients reported injecting insulin to control their diabetes. A total of 49% of these patients were taking more than one agent on a daily basis. The responses to the MARS (Horne, 2001) were summed. The maximum score for the scale is 30 representing optimal adherence. Scores on the scale ranged from 9-30 with 80.1% of the sample scoring above the median value of 29 (mean= 28.3). The distribution of scores is shown in Figure 4.2. Due to the skewness of the distribution scores were split at the median to indicate 'sub-optimal adherence' (>29, n =71) and 'optimal adherence' (≥ 29, n = 58) and for subsequent analyses.

Physical activity

Figure 4.3. Distribution of scores for patients on Baecke physical activity questionnaire scores (n=164).



The extent of physical activity in the sample revealed that only 28% of the sample engaged in activities other than walking, gardening and housework. Those engaging in other activities typically reported low intensity activities such as bowls and golf. The responses to the items on the two sub-scales derived from the Baecke physical activity were calculated. First, scores on the 'sport index' were calculated by multiplying the intensity code for the sport(s) engaged in (e.g. cycling (1.76) x duration (3 hours per week) x proportion of year (4 months) = 21.12) spent participating in that activity. This score was then added to the summed score of the remaining 3 items and the mean was derived. The summed score for the 4 items comprising the 'non-sport leisure index' were summed and the mean was derived. The mean scores for the 'sports index' and the 'non-sport leisure index' were added together to provide a total exercise score. Total scores (n=164) ranged from 2 to 17.7, the mean was 6.5 (3.2) and the median was 6.35 as shown in Figure 4.3. Due to the skewness of the data, the physical activity scores were split at the median to indicate 'less exercise' (< 6.35, n = 84) and 'more exercise' (≥ 6. 35, n = 80).

Dietary composition

Responses to the food frequency questionnaire were summed according to the McCance food codes (Holland et al., 1991) to determine energy derived from the major dietary components of fat, saturated fat, carbohydrate, sucrose, non starch polysaccharides (fibre), starch and fruit and vegetables. Energy values were calculated using a customised SPSS programme previously used for calculating dietary risk factors for heart disease in the context of primary care. The program calculates energy scores for each food group based on the following equation: frequency x portion size x nutrient composition (based on McCance foodcodes). The energy scores for each food group are expressed as percentage of energy per day and/or as gram per day as appropriate and are shown in Table 4.3.

Analysis of the responses to the food frequency questionnaire suggest that there was a disparity between total energy intake and patients' body weight (i.e., their reported energy intake was not adequate to sustain their reported body weight). Thus, a basal metabolic rate (BMR) was calculated using Schofield equations (Schofield et al., 1985) based on the age, gender and current bodyweight of individual participants to estimate the extent that participants were underreporting energy intake. This was achieved by calculating an acceptable energy intake and then multiplying BMR by a factor of 1.2. The result was then compared with the recorded energy intake in KJ. Subjects yielding energy scores higher than the recorded energy intake were identified as having energy intakes less than 1.2 x BMR and are thus regarded as under-reporters. This procedure revealed that 76% of respondents were classified as 'low energy reporters'.

Table 4.7. Mean (SD) percentage and/or grams per day for food groups derived from food frequency questionnaire (n=164)

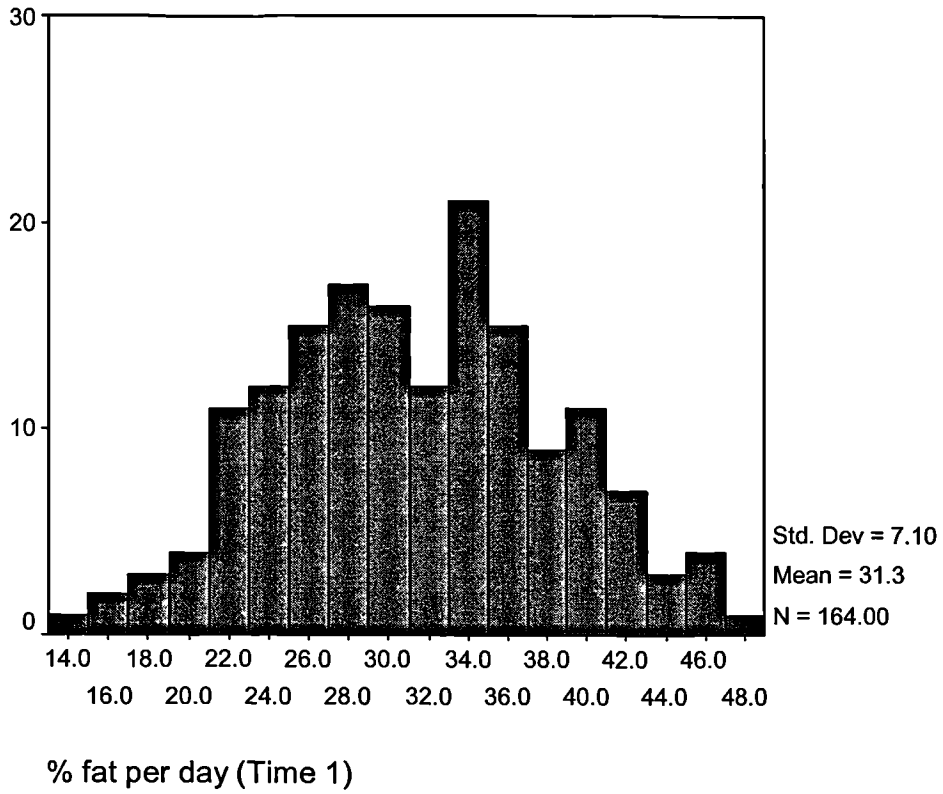
Food Type	Mean (SD) % per day	Mean (SD) grams per day (g/d)
Total Fat	30.8 (7.3)	62.1 (37.9)
Saturated Fat	11.2 (3.7)	22.6 (14.1)
Carbohydrate	46.7 (9.2)	229.3 (149.2)
Starch	28.4 (7.8)	140.3 (105.6)
Sucrose	6.96	33.5 (26.6)
Fibre	N/a	19.06 (14.7)
Fruit & Vegetables	N/a	398.9 (292.6)

A number of measures of dietary intake also showed skewed distributions and for consistency with the measures of medication and physical activity adherence were split into binary outcomes. Where applicable, binary dietary outcomes were based

on Health Education Authority daily intake 'target' cut-offs used in the development of the food frequency questionnaire (HEA3, Little et al, 2000).

Fat

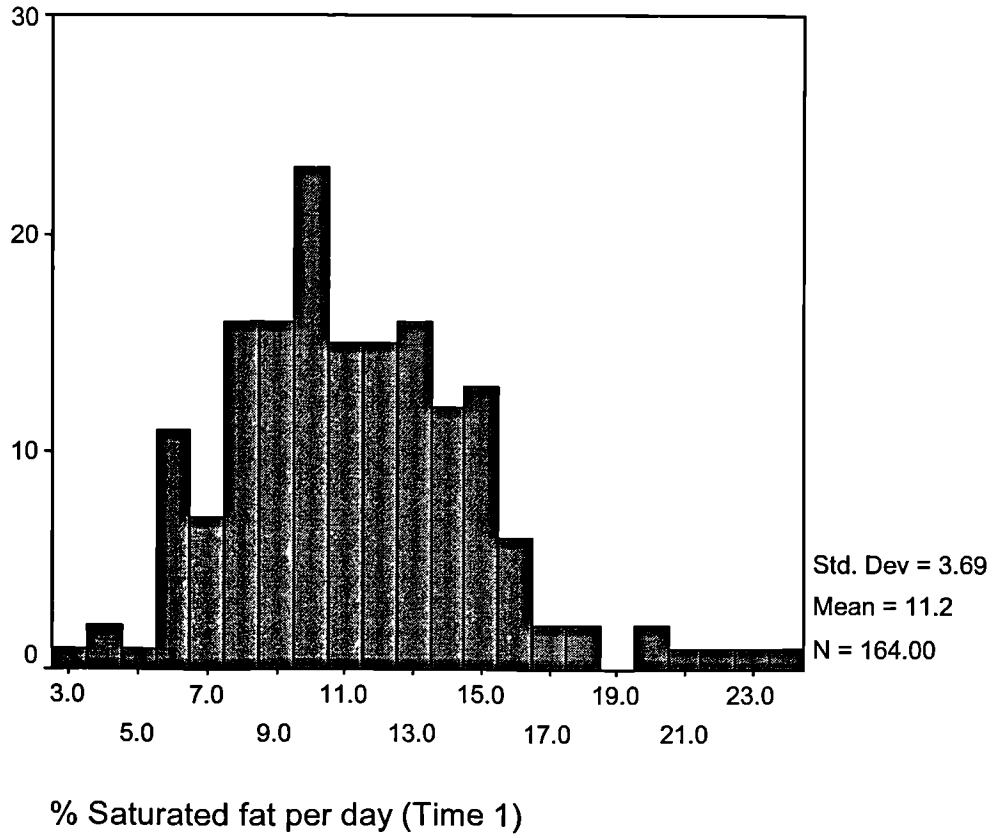
Figure 4.4. Distribution of scores for percentage of energy from fat per day (n= 164)



The recommended total fat intake is approximately 33% of total energy per day, therefore the scores were split at this value; 'low fat' intake was defined as < 33% (n = 91) and 'high fat' ≥ 33% (n = 71). The distribution of scores are shown in Figure 4.4.

Saturated Fat

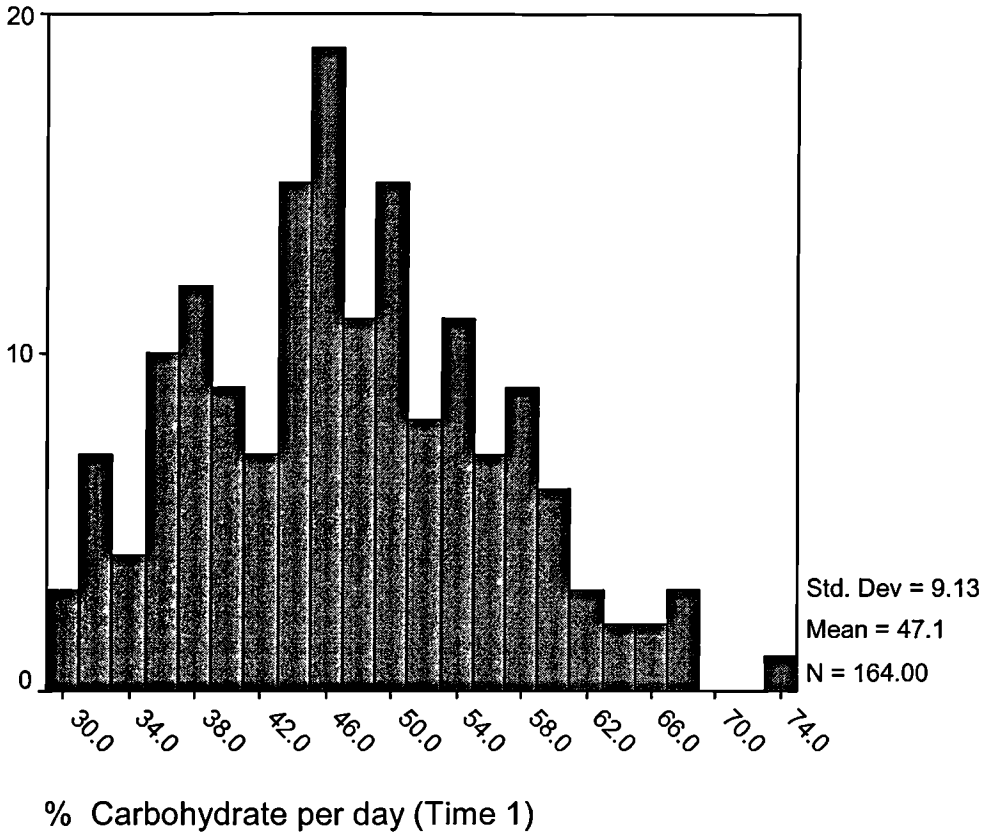
Figure 4.5. Distribution of scores for percentage of energy from saturated fat per day (n=164).



The recommended daily intake of saturated fat is approximately 10%, therefore scores were split at this value, scores < 10% indicate 'low' saturated fat intake (n = 87), scores ≥ 10% indicate 'high' saturated fat intake (n = 77) . The distribution of scores for percentage of saturated fat intake are shown in Figure 4.5.

Carbohydrate

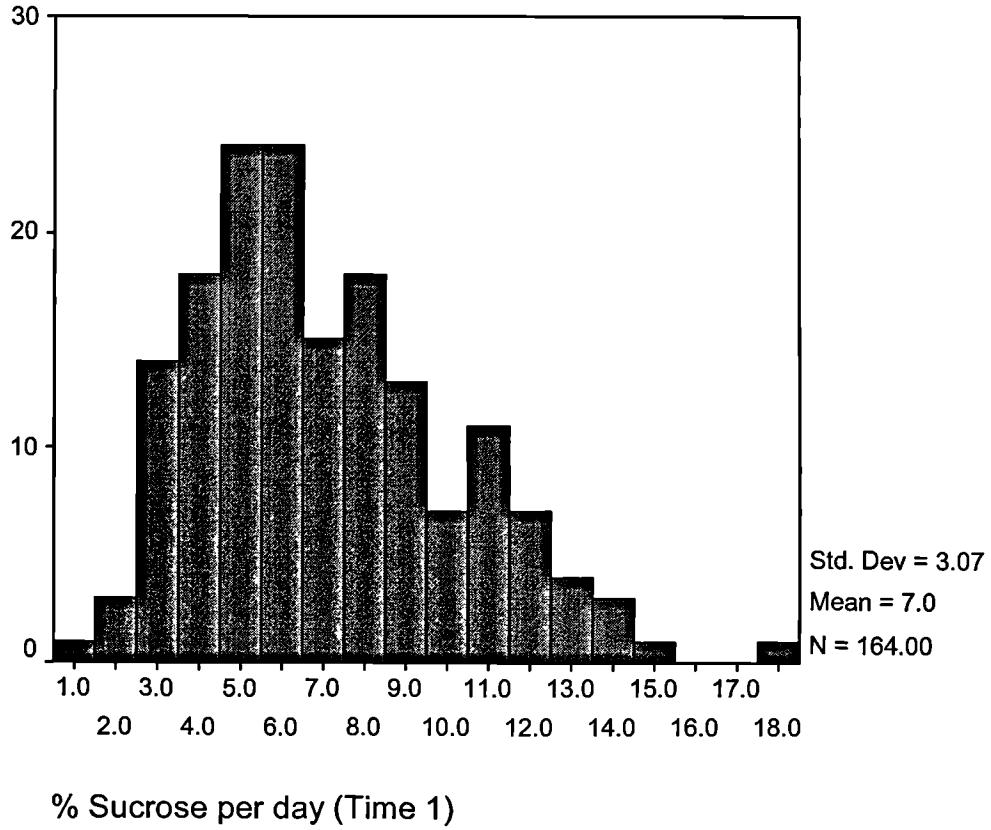
Figure 4.6. Distribution of scores for percentage of carbohydrate intake per day (n=164)



The recommended daily carbohydrate intake is approximately 50% thus the percentage scores were split at this value; 'low' carbohydrate intake was defined as < 50% (n = 102) and 'high' carbohydrate as ≥ 51% (n = 62). The distribution of scores for percentage of carbohydrate intake per day are shown in Figure 4.6.

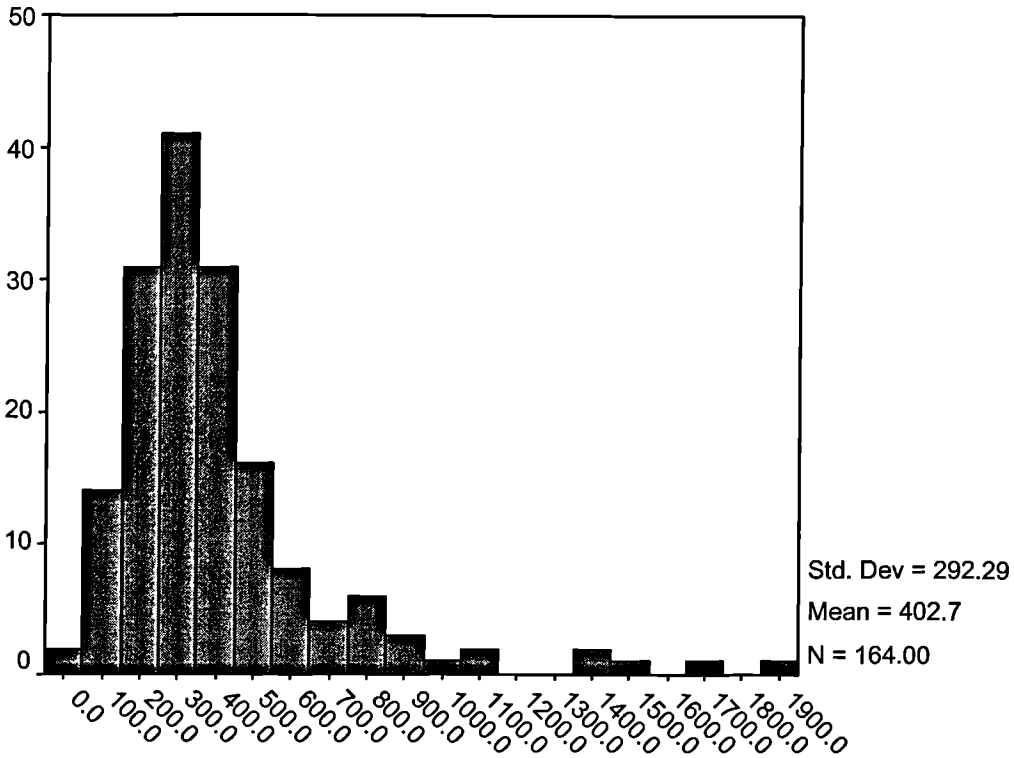
Sugar

Figure 4.7. Distribution of scores for percentage of sugar intake per day (n= 164)



The mean (7.0) and median (6.0) scores for simple sugars (sucrose) were below the daily target of 10% (reflecting one aspect of dietary behaviour which may have been underreported). However, for this variable scores were split at the recommended value; scores < 10% indicate 'low' sugar (n = 28) and scores ≥ 10% indicate 'high' sugar (n = 136). The distribution of scores for percentage of sugar intake per day are shown in Figure 4.7.

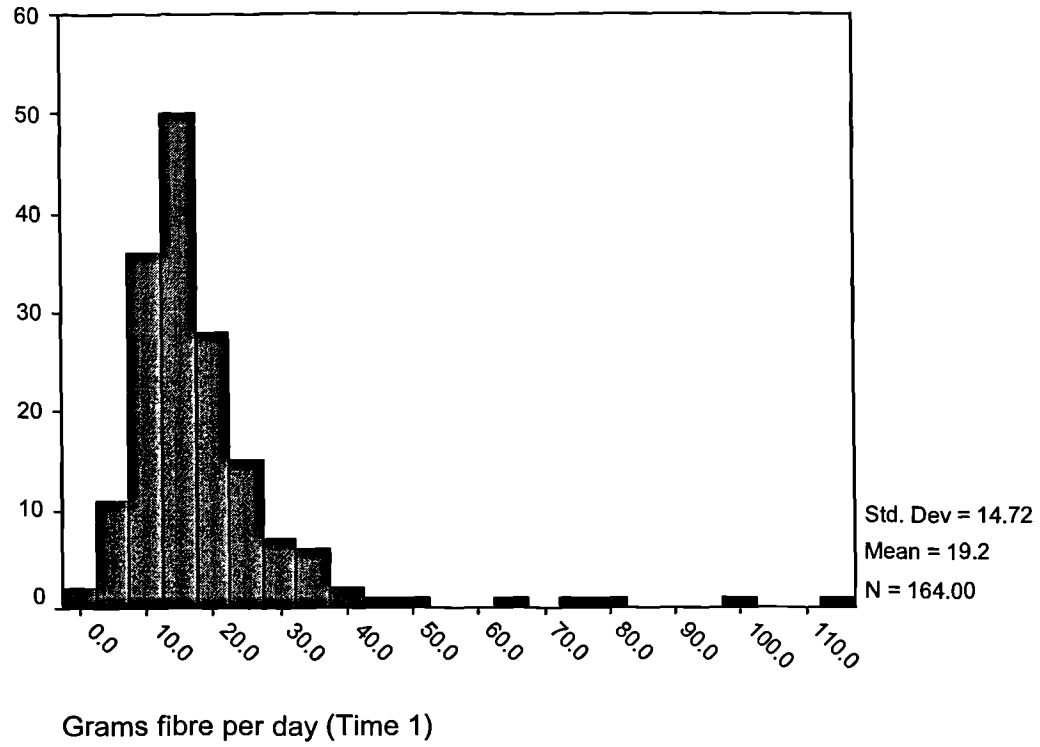
Figure 4.8. Distribution of scores for grams of fruit and vegetables consumed per day (n=164).



The mean score for fruit and vegetable intake reached the recommended 400 g/d (or 5 portions a day) and scores were split at this value. Therefore, 'low' fruit and vegetable intake was defined as < 400 g/d (n = 110) and 'high' intake as ≥ 400 g/d (n = 54). The distribution of scores for grams of fruit and vegetables consumed per day are shown in Figure 4.8.

Fibre

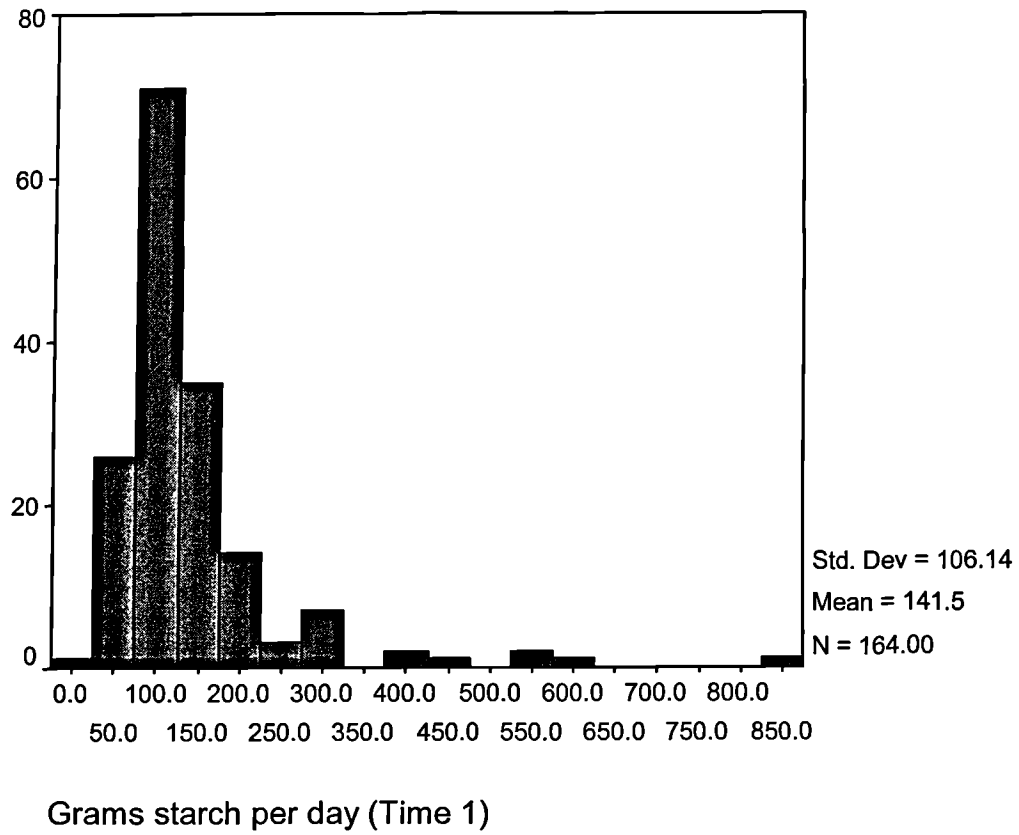
Figure 4.9. Distribution of scores for grams of fibre consumed per day (n=164).



Mean fibre intake was 19 g/d and therefore equivalent to the recommended 18g/d. Therefore the scores for fibre intake were split at <18 g/d indicate 'low-fibre' (n = 106) and scores ≥ 18 g/d indicate 'high-fibre' (n = 58). The distribution of scores for grams of fibre consumed per day are shown in Figure 4.9.

Starch

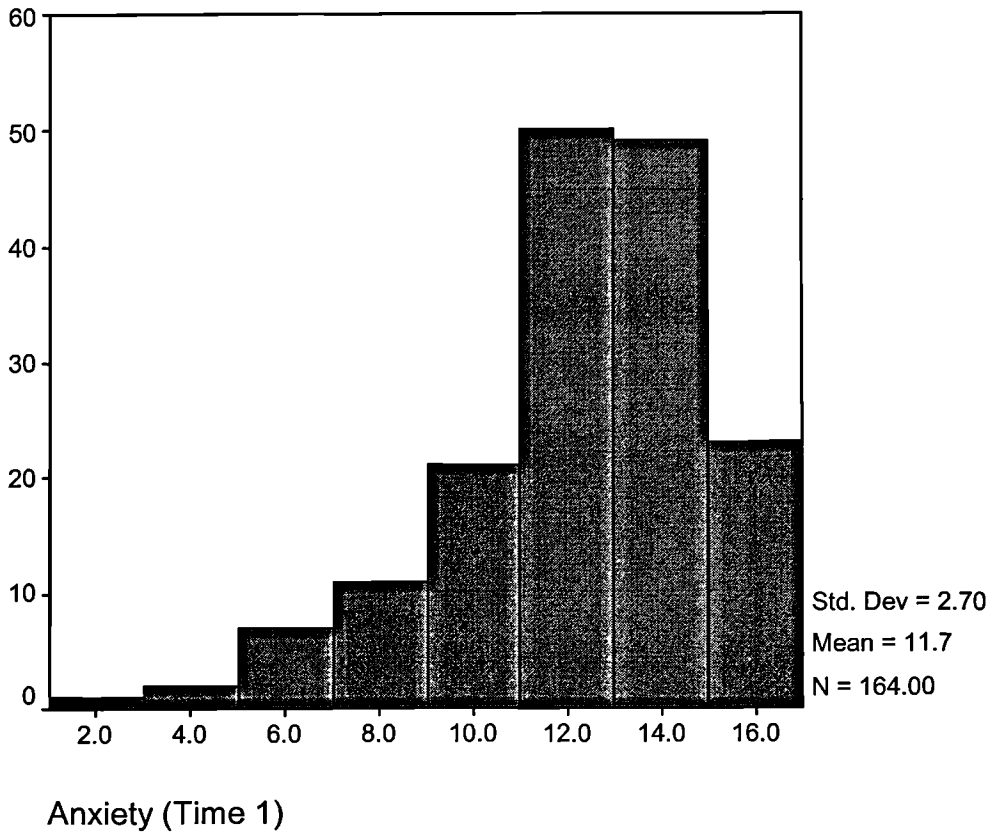
Figure 4.10. Distribution of scores for grams of starch consumed per day (n=164).



Finally, the mean starch intake (141.5 g/d) was well below the recommended 325g/d ('Diabetes UK' recommend regular meals based on starchy foods to control blood sugar). However, scores were split at the recommended value; scores < 325g defined 'low-starch' (n = 136) and 'high-starch' was defined as ≥ 325 g/d (n = 28). The distribution of scores for grams of starch consumed per day are shown in Figure 4.10.

Anxiety

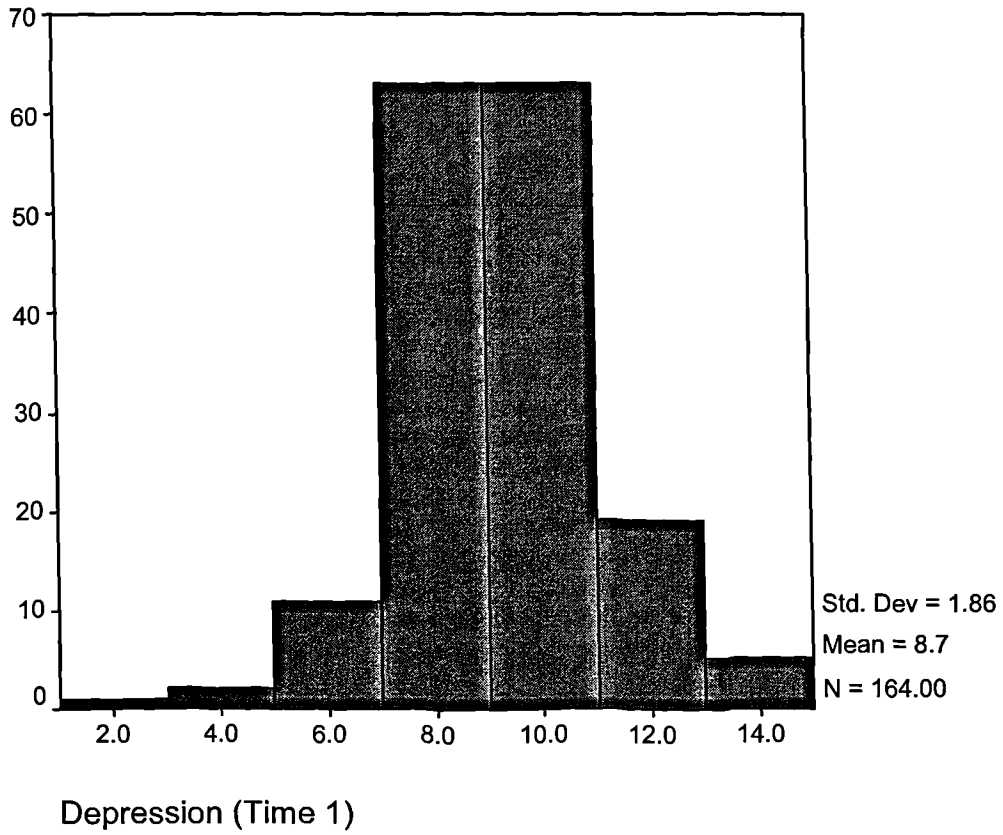
Figure 4.11 Distribution of scores for patients' levels of anxiety at time 1 (n=164).



Patients' responses to the anxiety sub-scale of the HADS were summed (n=164). Scores of 8-10 on the sub-scale indicate mild levels of anxiety, scores of 11 or higher indicate moderate to severe symptomatology equating to a clinically significant disorder. The distribution of anxiety scores in patients ranged from 2-16 with a mean of 11.7 (SD = 2.7, median=12). For analyses, anxiety scores were split at 11 to distinguish patients with clinically significant disorder, thus scores < 11 indicate low levels of anxiety (n = 42) and scores ≥ 11 indicate 'high' or clinically significant levels of anxiety (n = 122). The distribution of scores for anxiety are shown it Figure 4.11.

Depression

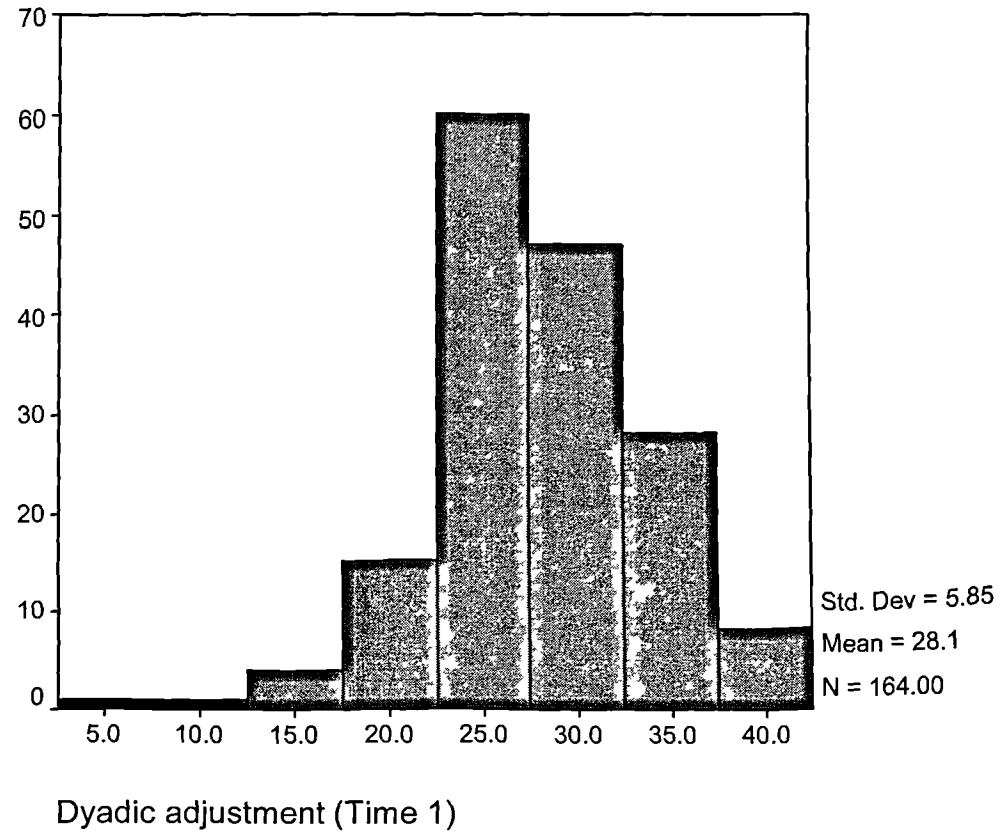
Figure 4.12 Distribution of scores for patients' levels of depression at time 1 (n =164).



Patients' responses to the depression sub-scale of the HADS were also summed (n= 164). As for anxiety, scores of 8-10 indicate mild levels of depression, scores of 11 or higher indicate moderate to severe symptomatology. Scores for depression ranged from 1-14 with a mean of 8.7 (SD = 1.86, median=9). It appears that psychological morbidity in the present population is very high and is expressed largely as clinically significant levels of anxiety and moderate to severe levels of depression. For analyses, scores for depression were split at 11 to distinguish clinically significant disorder, thus scores < 11 indicate 'low' levels of depression (n = 126) and scores ≥ 11 indicate 'high' or clinically significant levels of depression (n = 38). The distribution of scores for patients' levels of depression are shown in Figure 4.12.

Dyadic adjustment

Figure 4.13 Distribution of patients' dyadic adjustment scores at time 1 (n=164).



The responses for the Dyadic Adjustment Scale (DAS) were summed for all patients and partners (n=164). For patients, the distribution of scores ranged from 4 to 42 and the mean was 28.1 (SD= 5.8), median=28 and are shown in Figure 4.13. For partners, scores ranged from 13 to 42 and the mean was 28.2 (SD= 5.7), median=28. The scores on the DAS for patients and partners were highly correlated (Pearson *r.* = .6, p <.01). In addition t-tests demonstrated that there were no significant differences between patients' and partners' scores (t = -.197 (159), p =.844). It can, therefore, be concluded that there is a high degree of agreement between patients and partners regarding the quality of their relationships. Finally, for analyses patients' dyadic adjustment scores were split at the median value of 28, thus scores < 28 indicate 'poor' dyadic adjustment (n = 79) and scores ≥ 29 indicate 'high' dyadic adjustment (n = 85).

4.4. Representations of patients and partners

Differences between patients' and partners' representations

To test for differences between patients' representations of diabetes and those of their partners (n=164), a series of t-tests were performed for all of the dimensions measured. This procedure revealed significant differences for only 3 of the 14 illness representation dimensions; *personal control, illness coherence, and control-future,* the results are shown in Table 4.8. For *personal control* partners scored lower on this scale indicating that the patient believed they had more control (self-efficacy) of their diabetes (p <.05). Partners scored higher on the *illness coherence* dimension indicating that the patient had a poorer understanding of the condition (p < .01) relative to the partner. Finally, partners perceived a stronger belief in the importance of treatment in avoiding complications relating to diabetes in the future (p < .01).

Table 4.8. Results of t-tests for differences in patients and partners illness representations (n=164 patient-partner dyads)

	Mean (SD)		
Illness Representation	**Patient**	**Partner**	***T***
Timeline-acute	23.2 (4.8)	23.7 (4.3)	-.972
Timeline-cyclical	11.1 (2.8)	10.8 (2.8)	.823
Consequences	17.2 (3.8)	17.1 (3.6)	-.009
Personal control	23.4 (3.8)	23.1 (4.3)	2.100*
Treatment control	22.9 (4.6)	23.5 (3.5)	-1.349
Illness coherence	17.5 (4.6)	18.4 (4.3)	-2.461**
Emotional representations	12.1 (3.9)	12.6 (3.7)	-1.337
Identity-high bg	3.16 (2.2)	3.25 (2.3)	-.621
Identity-low bg	3.20 (2.2)	3.41 (2.4)	-.841
Control-now	60.9 (5.0)	61.0 (4.3)	-1.699
Control-future	60.9 (4.9)	61.9 (3.7)	-2.679**
Cause-behaviour	14.4 (4.0)	14.0 (4.4)	.647
Cause-external	12.7 (3.6)	12.6 (3.4)	.304
Cause-hereditary	3.17 (1.3)	3.11 (1.3)	.705

2 tailed significance; * = $p < .05$, ** = $p < .01$, df = 163

4.5. Relationship between illness representations and outcome measures: Independent t-tests

A series of independent t-tests were conducted to determine if significant differences existed for the representations of diabetes and their relationship with the scores for the behavioural and psychological outcomes.

Medication

For medication, patients with 'sub-optimal' levels of adherence held a stronger belief in perceived *consequences* (M= 17.9 vs 16.5 , t (127) = 2.11, p <.05) and reported greater *emotional representations* (M = 12.9 vs 11.4, t (127) = 2.37, p <.05). In addition, the importance of 'own behaviour '(M = 15.2 vs 13.5, t (127) = 2.33, p < .05), and 'external' factors as *causes* of diabetes (M = 13.5 vs 12.3, t (127) = 1.94, p <.05) were stronger in these patients. In contrast, patients reporting 'optimal' medication adherence demonstrated a stronger belief in the importance of *treatment* to control diabetes *now* (M = 61.8 vs 59.5, t (127) = -2.63, p < .05) and a belief that *treatment* would help to avoid *future* complications of diabetes (M = 62 vs 60.2, t (127) = -2.01, p < .01).

A number of partners' representations of diabetes were associated with 'sub-optimal' medication adherence. The partners held higher *time-line* beliefs, believing in a longer chronicity of diabetes (M = 24.9 vs 23.1, t (127) = 2.24, p <.05), greater perceptions of the patients' *personal control* (M = 23.4 vs 21.3, t (127) = 2.77, p <. 01), and *treatment control* beliefs (M =24.6 vs 23, t (127) = 2.44, p < .05). Finally, the partners of patients reporting 'optimal' adherence were more likely to endorse a belief that the patients' 'own behaviour' (M = 15.2 vs 12.9, t (127) =2.81, p < .01) and 'hereditary' factors were likely *causes* of diabetes (M = 3.4 vs 2.8, t (127) =2.37, p < .05).

Physical activity

The scores split for low and high levels of physical activity were also analysed using independent t-tests to determine whether significant differences exist for representations of diabetes. It was demonstrated that only one dimension was significant with regard to physical activity. Patients reporting higher levels of physical activity demonstrated stronger beliefs in *Personal control* of diabetes (M = 24 vs 22.7t (162) = -2.01, p <.05).

Dietary behaviour

A series of independent t-tests were conducted to examine patients' and partners' representations of diabetes with regard to the scores split at recommended values for patients' diet; saturated fat, total fat, carbohydrate, fibre, starch, fruit and vegetables and sugar.

Fat

For total fat intake, patients who were eating less fat believed that diabetes has more serious *consequences* (M = 17.8 vs 16.4, t (162) = 2.52, $p < .05$). Patients holding stronger beliefs that their 'own behaviour' was a *cause* of diabetes consumed more fat (M = 13.8 vs 15.1, t (162) = -2.19, $p < .05$). Partners of patients consuming less fat held a stronger belief in the chronicity of diabetes (M = 24.3 vs 22.8, t (162) = 2.22, $p < .05$).

Saturated fat

Patients who reported consuming less saturated fat had stronger beliefs regarding the *consequences* of diabetes (M = 17.8 vs 16.5, t (162) = -2.08, $p < .05$).

Fibre

Patients reporting high fibre consumption had stronger beliefs in the chronicity of diabetes as indicated by *time-line* scores (M = 24.6 vs 22.5, t (162) = -2.73, $p < .01$). These patients also held stronger beliefs in the serious *consequences* of their diabetes (M = 18.2 vs 16.3, t (162) = -2.71, $p < .01$). The partners of patients reporting high fibre consumption held higher *personal control* beliefs (M = 23.8 vs 22.1, t (162) = -2.86, $p < .01$).

Carbohydrate

For patients' consumption of carbohydrate there were no statistically significant representations of diabetes. However, the partners of patients reporting less than the recommended 50% carbohydrate in their diet held beliefs in *treatment control* (M = 24.1 vs 22.9, t (162) = 2.21, $p < .05$).

Starch

Patients reporting less consumption of starch in their diets held stronger *identity* perceptions when blood glucose was low (M = 3.28 vs 1.37, t (162) = 2.40, $p < .01$) and high (M = 3.29 vs 1.62, t (162) = 1.97, $p < .05$)

Sugar

A high sugar diet was more likely to be consumed by patients reporting more *illness coherence* (M = 18.0 vs 15.9, t (162) = -2.39 $p < .05$). Partners of patients reporting high sugar diets expressed stronger *treatment control* beliefs (M = 23.9 vs 22.5, t (162) = 2.18, $p < .05$) and were more likely to believe the patients 'own behaviour' was a cause of diabetes (M = 14.4 vs 12.7, t (162) = 1.98, $p < .05$). .

Fruit and vegetables

Partners of patients consuming less fruit and vegetables had a stronger belief in the treatment for controlling diabetes 'now' (M = 61.8 vs 59.4, t (162) = 3.290, $p < .01$).

Anxiety

For patients a number of diabetes representations were associated with levels of anxiety. First, *cyclical time-line* beliefs (M = 12.1 vs 10.7, t (162) = 2.64, $p < .01$), stronger beliefs in *consequences* (M = 18.4 vs 16.7, t (162) = 2.47, $p < .01$), and

stronger *emotional representations* (M = 14.6 vs 11.3, t (162) = 5.66, p <.001) were all associated with less anxiety. Patients' attributing the *cause* of diabetes to 'external' factors were also less anxious (M = 13.7 vs 12.4, t (162) = 3.37, p <.001). Patients reporting more symptoms when blood-glucose is high were more likely to experience clinically significant levels of anxiety (M = 3.97 vs 2.94, t (162) = 2.20, p <.05). Partners' representations of diabetes were not significantly associated with anxiety.

Depression

For patients only stronger beliefs in the *consequences* of diabetes was associated with clinically significant levels of depression (M = 18.5 vs 16.8, t (162) = -2.45, p < .05). Partners with stronger beliefs in the importance of *treatment* for controlling diabetes 'now' (M = 62.5 vs 60.6, t (162) = -2.341, p < .05) and for avoiding *future* complications of diabetes (M = 63.2 vs 61.6, t (162) = -2.83, p < .01) were associated with clinically significant depression in patients.

Dyadic adjustment

Patients' believing in a more chronic *time-line* (M = 24.3 vs 22.2, t (162) = -2.83, p < .01) and perceiving more *illness coherence* (M = 18.3 vs 16.5, t (162) =-2.43, p < .05) exhibited higher levels of marital adjustment. Patients with partners perceiving that the patient had more *personal control* also exhibited higher levels of marital adjustment (M = 23.4 vs 22.0, t (162) = 2.08, p < .05).

4.6. Predicting health behaviours and outcomes: Logistic regression analysis

As the outcome data relating to patients' health behaviours were split at recommended or clinical cut-offs it was necessary to use a method of analyses that accommodates binary dependent variables.

Thus, logistic regression analysis was employed to determine the relative contribution that patients' and partners' representations of diabetes made to the behavioural and psychological outcome variables. The patients' and partners' representations of diabetes were used as explanatory variables to predict health behaviours, psychological morbidity and dyadic adjustment after controlling for demographic and clinical variables. To control for the influence of demographic and clinical variables these were entered in the first block of the regression model. This was necessary as there was a wide variation in disease duration, years married or living together, the number of prescribed agents to control diabetes and patients' BMI scores. To establish the importance of the patients' representations of diabetes in relation to the study outcomes all variables were entered in the second block. In the third and final block all the partners' representations were entered to determine the importance of partners' representations of diabetes in relation to outcomes. In view of the focus of the present thesis it was considered most appropriate to enter the patients' representations before partners' representations to establish to what extent the partners' beliefs were predictive of management behaviours once the patients' representations were taken into consideration. This method was considered to be the most conservative approach and would provide a more robust test of the partners' representations in predicting behavioural and clinical outcomes.

With regard to statistical power it is generally considered that 10 participants are required per independent variable in the model (Tabachnick & Fidell, 1996). Each regression model included a total of 32 independent variables and, in practical terms, the sample size consisted of n=328 (n=164x2) as partners were included in each regression model. In addition, due to the number of potentially relevant independent variables a forward stepwise procedure was employed. This stepwise procedure was selected to reduce the number of independent variables entered into each stage of the regression model. Thus at each stage only the most pertinent variables are considered in the regression analyses (i.e variables

correlated with the dependent variable at p <.05). Therefore it is clear that there was adequate statistical power to run the regression models and also have confidence in the results. The results are presented in Table 4.9.

Table 4.9. Results of logistic regression to examine predictive utility of demographic and diabetes representations at time 1 on health behaviours and psychological morbidity.

	B	OR	*P*	95% CI
Medication				
Personal control	-.187	.829	.035	.697-.987
Emotional representations	-.221	.802	.009	.680-.947
Control 'now'	.167	1.181	.019	1.027-1.359
Physical activity				
BMI	-.071	.931	.027	.874-.992
Anxiety				
Emotional representations	-.208	.812	.005	.703 - .938
Identity - high bg	-.527	.590	.000	.457 - .762
Identity - low bg	-.305	.737	.006	.593 - .916
Depression				
Consequences	.178	1.194	.008	1.048 - 1.361
Cause - 'own behaviour'	-.156	.856	.012	.758 - .966
Control 'future' (partner)	.248	1.281	.018	1.044 - 1.572
Dyadic adjustment				
Years cohabiting	-.031	.970	.027	.943 - .997
Illness coherence	.098	1.103	.021	.806 - .905
Cause - 'own behaviour' (partner)	-.126	.006	.006	.806 - .965

Medication

To determine adherence to prescribed diabetes medication the medication scores of 'optimal' and 'sub-optimal' adherence were used as the dependent variable. In the first block patients' age, gender, years married, disease duration, number of prescribed medications, and BMI were entered. Patient representations were entered in the second block and partner representations were entered in the third block.

The final equation demonstrated that patients' beliefs in *personal control* ($p < .05$) and *emotional representations* ($p < .01$) were negative predictors of medication adherence. However, patients' beliefs in the treatment regimen to *control* diabetes 'now' was a positive predictor of medication adherence ($p < .05$). No demographic variables or partners' representations emerged as significant predictors of medication adherence.

Physical activity

A similar model was utilised to determine levels of physical activity. In the first block patients' age, gender, number of years married, disease duration, weight and BMI were entered, patient and partner representations were entered in the second and third block respectively. The final equation of this model demonstrated that those with a greater BMI were less likely to engage in physical activity ($p < .05$). None of the patient or partner representations of diabetes were significant predictors.

Anxiety

To determine which representations of diabetes predicted levels of psychological morbidity the same procedure was used as for physical activity.

The final equation demonstrated that lower levels of anxiety were predicted by *emotional representations* ($p < .01$), *identity* when blood-glucose is high ($p < .001$) and identity when blood-glucose is low ($p < .01$). None of the partners' representations emerged as predictors of levels of anxiety.

Depression

Patients perceiving stronger perceptions of the *consequences* of diabetes predicted clinically significant levels of depression ($p < .01$). In addition, patients believing that the *cause* of their diabetes was due to their 'own behaviour' predicted lower levels of depression ($p < .05$). Partners' beliefs in the importance of *treatment* for controlling the patients' diabetes in the *future* emerged as a predictor clinically significant depression ($p < .05$).

Dyadic adjustment

Dyadic adjustment in patients was negatively predicted by the duration of the marriage ($p < .05$), and positively predicted by levels of illness coherence ($p < .01$). Partners with strong beliefs that the patients' 'own behaviour' was a cause of diabetes negatively predicted dyadic adjustment ($p < .01$)

Table 4.10. Logistic regression analyses to examine predictive utility of diabetes representations at time 1 on dietary outcome.

	B	OR	*P*	95% CI
Starch (g/d)				
Identity – high bg	-.618	.539	.033	.305 - .902
Fibre (g/d)				
Disease duration	-.077	.917	.034	.863 - .994
Gender	-.110	.331	.022	.129 - 251
Consequences	.119	1.126	.030	1.012 - 1.253
Personal control (partner)	.120	1.127	.035	1.008 – 1.261
Fat (%/d)				
Consequences	-.101	.904	.037	.822 - .994
Cause – own behaviour	.106	1.112	.022	1.016 – 1.217
Saturated fat (%/d)				
Age	-.045	.956	.013	.923 - .990
Carbohydrate (%/d)				
Cause - Hereditary	.344	1.411	.021	1.054 - 1.888
Treatment control (partner)	-1.25	.883	.020	.794 - .981
Sugar (%/d)				
Personal control	-.111	.895	.036	.807 - .993
Fruit and vegetables (g/d)				
Control 'now' (partner)	-.161	.852	.001	.777 - .934

Diet

Regression analyses were also conducted to determine which representations of diabetes were predictors of dietary components. In the first block patients' age, gender, years married, disease duration, weight and BMI were entered, patient and partner representations were entered in the second and third block respectively. (The results are summarised in Table 4.5).

Saturated Fat

Intake of saturated fat was negatively predicted by age (p <.05) such that older participants consumed less saturated fats. None of the patients' or partners' representations of diabetes were significant predictors of saturated fat intake.

Fat

The patients' belief in the *consequences* of diabetes was a significant predictor (p <.05) of lower fat intake, whereas greater fat intake was predicted by a belief that their 'own behaviour' was *cause* of diabetes (p <.05).

Fibre

Intake of dietary fibre was negatively predicted by disease duration such that patients with a longer standing diagnosis consumed less fibre (p <. 05). Patients' gender also predicted lower fibre intake such that females were less likely to consume fibre (p <.05). Patients' holding stronger beliefs in the *consequences* of diabetes were predictive of higher fibre intake (p <.05). Finally, patients with partners holding stronger *personal control* beliefs also predicted higher fibre intake (p <.05).

Sugar

Patients' holding stronger beliefs in their *personal control* of diabetes were less likely to consume sugar ($p < .05$).

Starch

Patients perceiving greater symptoms when blood-glucose is *high* were less likely to consume starchy foods ($p < .05$).

Carbohydrate

The consumption of carbohydrates was more likely if patients had a strong belief in 'hereditary' factors with regard to the *cause* of diabetes ($p < .05$) and less likely if partners had a strong belief in *treatment control* ($p < .05$).

Fruit and vegetables

Finally, patients whose partners held a strong belief in the importance of the treatment for controlling the patients' diabetes *now* were less likely to consume recommended levels of fruit and vegetables per day ($p < .05$).

4.6. Summary

The results have provided an indication of the relative importance of the representations of patients with type 2 diabetes and their partners. From this first phase of data collection two main issues emerged from the analyses. First, the data demonstrate that patients and partners are largely in agreement with regard to their beliefs about diabetes as significant differences were identified for only one of the 5 'core' dimensions of illness representation, namely *personal control*. Second,

the results have highlighted how patients' and partners' representations of diabetes are associated with aspects of patients' self-management of diabetes and psychological morbidity.

Relationship between patient and partner representations

Considering patients' and partners' representations first, significant differences were found for only 3 of the 14 diabetes-specific dimensions, namely; *personal control, illness coherence,* and *control–future* (efficacy of treatment to avoid future complications). The direction of the relationships indicated that partners were less likely to believe that patients have the ability to control their illness (self-efficacy). Partners also believed that patients had a less clear understanding of diabetes. More positively, partners were more open to believing that the patients' treatment would assist in avoiding future complications arising from diabetes.

Representations as predictors of self-management

It is clear, to some extent, that partners' representations may influence how the patient manages their disease and was explored through independent t-tests and logistic regression analyses. Turning first to medication adherence, partners held higher *time-line, personal control, treatment control* beliefs than patients. This suggests that partners held more realistic beliefs with regard to the chronicity of diabetes, and believed in the patients' ability to control the disease and that the treatment was effective. Such beliefs appear to be counter-intuitive considering these partners' beliefs were associated with patients reporting 'sub-optimal' adherence. There was, however, consensus with regard to *cause,* as both partners and patients were more likely to endorse the patient's 'own behaviour' as a cause of diabetes. However, logistic regression analyses demonstrated that partners' representations did not emerge as significant predictors of patients' medication adherence after controlling for demographic and patient variables.

In contrast to medication adherence, levels of intentional physical activity were low and likely to be due to the age and the high incidence of co-morbidity in the sample. Nevertheless, physical activity was positively associated with partners' representation of the patients' *personal control* beliefs. Furthermore, regression analysis demonstrated that BMI was a negative predictor of physical activity. Therefore, patients engaging in exercise were not hindered by advancing age but by increasing body mass. It is speculated that such low levels of reported activity may have prevented the identification of significant predictors.

The cornerstone of the treatment regimen for type 2 diabetes is the maintenance of a 'healthy' diet. It is this aspect of the treatment regimen which one would expect to involve a partner the most due to social norms and the context in which meals are consumed. For patients, stronger beliefs in the *consequences* of diabetes were associated with less consumption of saturated and total fat and more fibre. Partners' with stronger *time-line* beliefs were associated with less fat intake in patients, belief in *personal control* was associated with higher fibre consumption and partners' *treatment control* beliefs were associated with less carbohydrate consumption. With regard to sugar consumption, patients with partners expressing stronger *treatment control* beliefs consumed higher sugar diets and partners were more likely to attribute the condition to the patients' 'own behaviour'.

Once logistic regression analyses were conducted it was revealed that patients' beliefs in the *consequences* of diabetes significantly predicted reduced fat intake and greater fibre intake. Stronger *time-line* beliefs also predicted greater fibre intake. In addition, patients' perception of the degree of *personal control* they had over their diabetes predicted lower sugar intake whereas higher carbohydrate consumption was predicted by beliefs that diabetes has a hereditary component with regard to *cause*.

It was evident that partners' representations had a degree of influence on patients' dietary behaviour. Patients were likely to consume less than recommended levels of carbohydrate if their partners believed they held strong *treatment control* beliefs and more likely to consume carbohydrates if the *cause* of diabetes was believed to be 'hereditary'. Furthermore, patients were less likely to consume fruit and vegetables if their partners had a stronger belief in *treatment* to control diabetes *now*. It is, however, debatable to what extent carbohydrate consumption is detrimental to good management of diabetes. In conclusion, the results provide evidence that patients' representations of diabetes impact on medication, physical activity and dietary behaviour. However, more importantly it appears that partners' representations are also predictors of the patients' management behaviours after the influence of patients' representations of diabetes.

Representations and psychological morbidity

It is clear that high levels of anxiety were prevalent in the patients in this study and were greater than those reported for depression. This was reflected in the number of significant patients' representations of diabetes that were associated with anxiety. Interestingly, *emotional representations* and perceived *identity* when blood-glucose was *low* and *high* were associated with less anxiety.

Patients' with stronger beliefs in the *consequences* of diabetes were more likely to suffer with depression but were less likely to do so if that believed the *cause* was due to their 'own behaviour'. It appears that patients who have a less optimistic view of their condition are more likely to suffer with depression but may fare better if they take some responsibility for the onset of the disease.

Partners' representations of the importance of *treatment* to control diabetes *future* was, however, associated with depression in patients and emerged as a positive

predictor in the regression analysis. This is difficult to interpret but may mean that although partners' have a strong belief in the outcome of treatment, patients' may not share such optimism which may, in turn, contribute to greater depression.

Representations and dyadic adjustment

It is interesting to note that levels of dyadic adjustment in patients were negatively predicted by the duration of the marriage and were greater in patients with higher levels of illness coherence. In addition, partners with strong beliefs that the patients' 'own behaviour' was a cause of diabetes negatively predicted dyadic adjustment. Such results suggest that representations of diabetes have important implications for the marital relationship. Indeed, it would appear that happier relationships are enjoyed by patients in less established relationships, have a better understanding of the condition with partners who do not view the onset of diabetes as being the fault of the patient.

4.7. Conclusions

It is not clear whether or how patient and partner representations interact. However, in the logistic regression analyses it was either patient or partner representations that were associated with a particular outcome variable which may be a function of the extent that patient and partner representations were correlated. The direction of the observations are not certain as the data are cross-sectional. Nevertheless, it is clear that partners' representations play a role in some aspects of patient behaviour and psychological well-being. The stability of diabetes representations and their predictive utility will be examined prospectively with the 12-month follow-up data.

CHAPTER 5: RESULTS - TIME 2

5.1. Introduction

The analysis and findings of the time 1 data were described in Chapter 4. This chapter will describe the patient-partner diabetes representations and patients' behavioural and psychological outcomes assessed at time 2. In particular, this chapter describes the stability of patient-partner diabetes representations, differences between patients' and partners' representations, and the utility of representations assessed at time 1 in predicting patients health behaviours controlling for previous levels of adherence with the recommended behaviours. As at time 1 the relationship between patient-partner representations in relation to measures of psychological morbidity and dyadic adjustment are also assessed.

Follow-up population

All patients and partners participating at time 1 were contacted again approximately 12 months later (12-14 months) and invited to complete follow-up questionnaires and provide a blood sample for the study. The slight variation in follow-up was for two logistical reasons. Firstly, patients were invited to attend a clinic based on their geographical location (Bristol or Weston-Super-Mare) to provide blood samples and secondly to ensure that the collection of the blood sample coincided with the completion of the follow-up questionnaires.

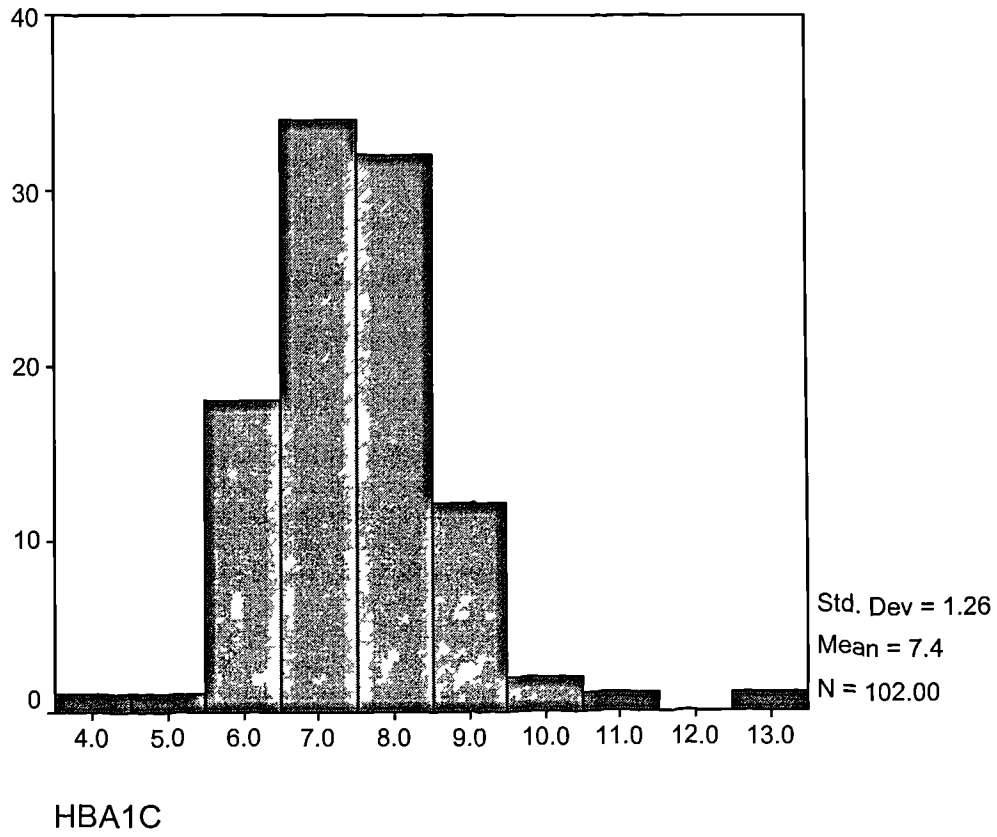
The follow-up questionnaire booklet assessed representations of diabetes and self-reported levels of diet, exercise, medication, psychological morbidity, dyadic adjustment, BMI and was identical to that used at time 1. Of the original 164 patient-partner dyads, 134 dyads completed the time 2 questionnaire booklet thus yielding a response rate of 81%. Of these 134 patients a total of 102 consented to provide a blood sample for the study (a response rate of 76%).

Independent t-tests were conducted to determine if differences existed between the characteristics and diabetes representations of patient-partner dyads completing questionnaires at time 1 only (n=30) compared with those completing at both time-points (n=134). No significant differences were found for age, years cohabiting, disease duration, weight, BMI and number of prescribed medications. Significant differences were found, however, for patients' representations of diabetes. The degree of *illness coherence* for patients assessed at both time-points was less than those assessed at time 1 only ($t(162) = -2.12$, $p < .05$). Patients assessed at both time-points also held stronger beliefs that the *cause* of diabetes was hereditary ($t(162) = -2.15$, $p < .05$). Partners assessed at both time-points exhibited stronger beliefs in the patients' *personal control* of diabetes ($t(162) = -2.57$, $p < .01$). Descriptive statistics for patient and partner representations of diabetes at both time-points are shown in Table 5.1.

HbA1c

All assays of HbA1c (n=102) were processed using the Menarini-Arkray HA 8140 haemoglobin A1c analyser (John et al., 1997) at the Department of Clinical Biochemistry, Bristol Royal Infirmary. The distribution of scores for HbA1c ranged from 4.20% to 12.9% the mean was 7.4 (SD=1.26), the median was also 7.4 (see Figure 5.1). Only 14% of scores fell within the recommended range for HbAlc (between 4% and 6%). A further 56% of scores fell between 6% and 8%. Thus, overall, patients who consented to HbA1c testing were considered to be in reasonable control of their disease. Nonetheless, 30% of the sample had elevated HbA1c scores (i.e., > 8%). The score were split at the median value of 7.4% for subsequent analyses (<7.4% = better control, n = 55, > 7.5% = poorer control, n = 47).

Figure 5.1 Distribution of scores for HbA1c at time 2 (n=102)



5.2. Stability of diabetes representations between time 1 and time 2

A series of t-tests were conducted to examine if differences existed between patients representations of diabetes at time 1 and time 2 (descriptive statistics are shown in Table 5.1). It is evident that scores for a number of representations of diabetes remained stable over the 12-14 month follow-up period (see Table 5. 2). These stable representations were *cyclical time-line, illness coherence,* and *cause.* In addition, the degree of perceived symptoms related to the illness when blood glucose was low or high as measured by the *identity* sub-scales did not did change between time and time 2. However, significant increases between time 1 and time 2 were evident for patients' *time-line* scores and *emotional representations* indicating

that patients viewed their diabetes as lasting longer and having a bigger emotional impact at time 2. A significant decrease was evident for perceived *consequences,* and beliefs in *personal control, treatment control,* and the importance of treatment to control diabetes *now* between time 1 and time 2. Thus, patients viewed their diabetes as having fewer serious consequences and being less amenable to control at time 2.

Stability of partners' representations from time 1 to time 2

Differences in partners' representations also emerged between time 1 and time 2. Increased *time-line* beliefs reflected the chronicity of diabetes at time 2. Additionally, *personal control, treatment control* and *control-future* beliefs also decreased indicating that partners viewed the patients' diabetes as lasting longer and was less controllable at time 2. Partners' beliefs that the patient's 'own behaviour' was a *cause* of diabetes also increased over the follow-up period. However, no significant changes were evident for partners' representations regarding perceived *consequences* of diabetes and the importance of treatment to control diabetes *now.* The results are shown in Table 5.2.

Table 5.1. Descriptive statistics for diabetes representations for patients and partners at time 1 (n=134) and time 2 (n=134).

	Time 1 (n=134)		Time 2 (n=134)	
Representation	**Patient**	**Partner**	**Patient**	**Partner**
Timeline-acute	23.4 (4.1)	22.9 (4.0)	24.8 (4.3)	25.1 (3.5)
Timeline-cyclical	11.6 (3.4)	10.5 (4.1)	10.8 (3.2)	10.5 (3.0)
Consequences	17.3 (4.0)	17.0 (4.5)	16.3 (4.1)	16.5 (3.7)
Personal control	22.6 (3.9)	20.6 (5.1)	21.2 (4.0)	21.1 (3.3)
Treatment control	22.3 (5.2)	23.9 (3.5)	19.8 (3.0)	20.1 (3.2)
Illness coherence	16.0 (4.3)	17.6 (4.3)	17.7 (4.9)	18.3 (4.3)
Emotional reps	12.6 (3.9)	12.6 (5.1)	14.6 (4.7)	15.5 (5.1)
Control-now	60.2 (5.8)	61.9 (3.2)	58.4 (6.7)	60.5 (5.4)
Control-future	61.0 (4.9)	62.5 (3.0)	59.3 (6.1)	60.1 (6.5)
Cause-behaviour	14.7 (3.2)	14.5 (3.7)	14.2 (4.2)	15.7 (4.4)
Cause-external	13.3 (3.5)	12.6 (3.5)	12.1 (3.7)	12.1 (3.9)
Cause-hereditary	2.8 (1.2)	3.0 (1.3)	3.35 (1.3)	3.28 (3.9)
Identity-high bg	3.6 (2.3)	3.4 (1.9)	3.02 (2.0)	3.33 (2.2)
Identity-low bg	3.5 (2.5)	2.7 (2.3)	3.41 (2.5)	3.31 (2.5)

Differences between patients' and partners' representations of diabetes from time 1 to time 2

A series of t-tests were also conducted to identify if significant differences exist between patients' and partners' representations of diabetes at follow-up, the results are shown in Table 5.2. It was found that partners held stronger beliefs in the importance of *treatment* to control diabetes *now* and partners' also held a stronger belief that the patients' 'own behaviour' was a *cause* of diabetes. At time 2 the differences between patient and partner representations were not consistent with the results of time 1 which found differences between patients and partners for three dimensions; *illness coherence, personal control,* and the importance of *treatment* to avoid *future* complications of diabetes.

Table 5.2. Summary of t-tests comparing. patient and partner diabetes representations between time 1 (n = 134) and time 2 (n =134) and results of t-tests for differences between patients and partners at time 2

Representation	T1 to T2 Patient (t)	T1 to T2 Partner (t)	Patients versus partners at Time 2 (t)
Timeline-acute	-3.176** ↑	- 3856*** ↑	-.640
Timeline-cyclical	1.312	. 059	.695
Consequences	2.510* ↓	1.509	-.148
Personal control	6.493*** ↓	4.653*** ↓	-1.02
Treatment control	8.996*** ↓	8.141*** ↓	-1.90
Illness coherence	.311	. 931	-3.24
Emotional representations	-7.384***↑	-4.969*** ↑	-1.46
Control-now	3.729*** ↓	.985	-3.24**
Control-future	3.039** ↓	2.220* ↓	-.415
Cause-own behaviour	.399	-3.638*** ↑	-2.89*
Cause-external	1.342	.961	-.415
Cause-hereditary	-.366	-.874	.596
Identity-high bg	1.237	-.571	.042
Identity-low bg	-.198	.707	-1.13

p <.05, ** p <.01, *** p <.001, Time 1 df = 133, Time 2 df = 133
Note: ↑ ↓ = Direction of change

Dyadic adjustment

Dyadic adjustment for patients at time 2 remained stable with a mean of 27.8 (6.8) compared with 28.1 (5.8) at time 1 (t (133) = -.727, p >.05). Scores for partners also remained stable with a mean of 28.7 (6.1) compared with 28.2 (5.7) at time 1 (t (133) = .376, p >.05). As at time 1, there was no significant difference in dyadic adjustment between patients' and partners' scores at time 2 (t (133) = -.687, p >.05).

Body Mass Index

Mean body weight at time 2 was 87. 2 kg (SD=29.6) compared with 91.8 kg (17.7) at time 1. This weight reduction at time 2 also equated to a reduced mean BMI of 29.5 (Range = 19-47, SD=6.2) compared with 32.2 (Range = 17-48, SD=5.53) at time 1. At time 2 a total of 76.5% of the sample score above the cut-off for being overweight of >25 compared with 90% at time 1. However this apparent weight reduction was not statistically significant when t-tests were conducted on BMI scores (t (97) = 1.42, p >.05).

5.3. Stability of outcome measures between time 1 and time 2

Diet

The descriptive data for the 7 dietary components assessed in the study are shown in Table 5.3. A series of t-tests demonstrated that the dietary components of percentage of fat, saturated fat, sugar and carbohydrate per day, and grams of fruit and vegetables per day showed no significant differences between time 1 and time 2. However, patients were consuming significantly less starch (p < .05) and fibre (p <.05) per day in their diets when assessed at 12-14 months.

The percentage of patients underreporting energy intake at time 2 was 72.5% compared with 76% at time 1. However, this reduction was not statistically significant (t= -5.05, p >.05).

Table 5. 3. Comparison of dietary intake for patients at Time 1 (n=134) and Time 2 (n=134)

Food Type	Time 1 Mean % per day	Time 2 Mean % per day	Time 1 Mean grams per day (g/d)	Time 2 Mean grams per day (g/d)	t
Total Fat	30.8 (7.3)	31.4 (8.0)	62.1 (38)	60.7 (38)	-1.02
Saturated Fat	11.2 (3.7)	11.3 (3.8)	22.6 (14.1)	22.1 (15.3)	-.666
Carbohydrate	46.7 (9.2)	46.9 (9.9)	229.3 (149.2)	212.1 (132.7)	-.047
Starch	28.4 (7.8)	27.9	140.3 (105.6)	123.4 (67)	1.961*
Sugar	6.96	7.22 (3.4)	33.5 (26.6)	34.0 (34.3)	-.920
Fibre	n/a	N/a	19.06 (14.7)	16.5 (8.8)	2.217*
Fruit & Vegetables	n/a	N/a	398.9 (292.6)	359.2 (243.9)	1.763

*p <.05, df =133

Table 5. 4. Descriptive data for physical activity, medication and psychological morbidity at time 1 (n=134) and time 2 (n=134)

Variable	Time 1 Mean (SD)	Time 2 Mean (SD)	t
Physical Activity	6.36 (3.28)	7.56 (3.03)	-5.110***
Medication	28.3 (3.21)	27.9 (5.0)	.652
Anxiety	11.6 (2.8)	9.71 (1.97)	7.068***
Depression	8.65 (1.97)	10.8 (2.02)	-9.008***

*** p <.001, df =133

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Physical activity

The mean score for physical activity significantly increased ($p < .001$) from time 1 to time 2 (see Table 5.4).

Medication

Self-reported medication adherence remained very high and did not change significantly between time 1 and time 2 (see Table 5.4).

Anxiety and depression

Scores for the anxiety sub-scale of the HADS decreased ($p < .001$) between time 1 and time 2 while scores for depression increased ($p < .001$), as shown in Table 5.4.

5.4. Prospective relationships between diabetes representations at time 1 and outcome measures at time 2: Independent t-tests

As at time 1, a series of independent t-tests were conducted to examine the prospective relationships between diabetes representations at time 1 and the outcome variables pertaining to diet, physical activity, medication adherence and psychological morbidity. For consistency, the scores for these outcome measures were split as at time 1. In addition, the relationship between diabetes representations and blood-glucose control (HbA1c) was also examined.

Medication

Patients' with stronger representations of *personal control* at time 1 ($M = 24.0$ vs 22.5,$t(106) = 2.06$, $p < .05$) and *illness coherence* ($M = 19.0$ vs 17.2, $t(106) = 2.02$, $p < .05$) had 'sub-optimal' adherence to medication at time 2. Whereas patients believing more strongly in the importance of *treatment* to control diabetes *now* had

'optimal' medication adherence (*M* 61.8 vs 59.9, t (106) = -2.01, p <.05). No significant relationships were found between medication adherence and partners' representations.

Physical activity

Patients with stronger perceived *time-line* (*M* = 24.1 vs 22.2, t (132) = -2.19, p <.05) and beliefs in the importance of *treatment* for avoiding *future* complications of diabetes at time 1 (*M* = 61.7 vs 59.8, t (132) = -2.25, p <.05) engaged in higher levels of physical activity at time 2. For patients whose partners held a greater, *cyclical time-line* (*M* = 11.2 vs 10.1, t (132) = 2.16, p <.05) and a belief that patients' 'own behaviour' was a *cause* of diabetes at time 1 engaged in less physical activity at time 2 (*M* = 14.7 vs 13.1= t (132) =1.95, p <.05).

Anxiety

Patients' perceiving greater symptoms of diabetes when blood-glucose was *high* (*M* = 4.30 vs 2.58, t (132) = -4.65, p <.001) and *low* (*M* = 4.0 vs 2.64, t (132) = -3.28, p <.01) at time 1 experienced clinically significant levels of anxiety at time 2. There were no significant relationships between partners' representations of diabetes and patients' levels of anxiety.

Depression

Patients with stronger *cyclical time-line* beliefs (*M* = 11.5 vs 10.3, t (132) = -2.55, p <.05) and *emotional representations* (*M* = 12.6 vs 11.3, t (132) = -2.13, p <.01) at time 1 experienced clinically significant levels of depression at time 2. There were no significant differences between partners' representations of diabetes and patients' levels of depression.

Fruit and vegetables

Patients with greater *time-line* beliefs at time 1 had a high consumption of fruit and vegetables at time 2 (M = 24.8 vs 22.9, t (132) = -2.43, p <.05). Patients with partners' with greater *time-line* beliefs also consumed more fruit and vegetables (M = 25.5 vs 23.5, t (132) = -2.69, p <.05) of diabetes. However, patients with partners' perceiving greater symptoms when blood glucose is *high* (M = 3.68 vs 2.46, t (132) = 2.93, p <.01) and held stronger beliefs in *treatment* to avoid complications in the *future* (M = 62.5 vs 61.1, t (132) = 2.23, p < .01) consumed less fruit and vegetables at time 2.

Fat

There were no differences in the initial diabetes representations between high and low fat consumers at time 2. However, patients whose partners demonstrated greater beliefs in *treatment control* had higher fat consumption (M = 24.7 vs 23.1, t (132) = -2.66, p <.01).

Saturated Fat

Patients with stronger *identity* scores when blood glucose is high at time 1 consumed more saturated fat at time 2 (M = 3.38 vs 2.63, t (132) = 2.03, p < .01). Patients with partners holding stronger beliefs in the patients' *personal control* of diabetes at time 1 consumed less saturated fat consumption at time 2 (M = 24.1 vs 22.8, t (132) = 2.10, p < .05).

Carbohydrate

There were no differences in the initial representations of diabetes between low and high consumers of carbohydrate at time 2. Patients with partners perceiving

stronger *emotional representations* of diabetes at time 1 consumed less carbohydrate at time 2 (M = 12.7 vs 11.0, t (132) = -2.15, p <.05). In addition, patients with partners' perceiving that 'own behaviour' was a *cause* of diabetes at time 1 consumed more carbohydrate at time 2 (M = 15.3 vs 13.2, t (132) = -2.58, p <.01).

Sugar

Patients' with greater beliefs in *treatment* to control diabetes *now* (M = 61.9 vs 59.6, t (132) = -2.03, p < .05). and to avoid *future* complications (M = 62.8 v 60.5, t (132) = -2.22, p < .05) at time 1 were greater consumers of sugar at time 2. Patients with partners' reporting stronger beliefs in patients' *personal control* of diabetes at time 1 consumption more sugar at time 2 (M = 25.0 vs 23.0, t (132) = -2.47, p <.01). However, patients with partners perceiving the *consequences* of diabetes to be more serious at time 1 consumed less sugar at time 2 (M = 17.2 vs 15.4, t (132) = 2.80, p < .05). Finally, patients with partners perceiving a stronger illness *identity* when blood glucose is high at time 1 consumed less sugar at time 2 (M = 3.44 vs 2.40, t (132) = 3.07, p < .01).

Starch

There were no differences in the initial representations of diabetes for patients or partners with regard to starch intake at time 2.

Fibre

Patients consuming higher proportions of fibre in their diet at time 2 held stronger *time-line* beliefs (M = 25.1 vs 22.9, t (132) = -2.73, p <.01) and perceived *consequences* at time 1 (M = 18.4 vs 16.7, t (132) = -2.41, p <.05). Patients with partners holding stronger perceptions of the patients' belief in *personal control* (M = 25.1 vs 22.7, t = -3.66, p <.001) and *treatment control* (M = 25.0 vs 23.2, t (132) = -2.96, p <.01) at time 1 consumed more fibre at time 2. Less fibre consumption by patients at time 2 was

more likely if partners reported that patients' experienced stronger *emotional representations* of diabetes at time 1 (M = 12.7 vs 10.7, t (132) = 2.57, p <.01).

Dyadic adjustment

Patients' with stronger *emotional representations* at time 1 were reported more dyadic adjustment at time 2 (M = 12.3 vs 10.8, t (132) = 1.94, p <.05).

HbA1c

Patients' reporting more symptoms when blood glucose was high (M = 3.50 vs 2.69, t (100) =2.62, p <.01) and greater beliefs in an 'external' *cause* of diabetes at time 1 (M = 13.5 vs 11.5, t (100) = -2.59, p <.05) had poorer control of blood-glucose at time 2 (higher HbA1c scores). Patients with partners endorsing 'hereditary' factors as a *cause* of diabetes at time 1 (M = 3.31 vs 2.76, t (100) = -2.09, p <.05) also had poorer control of blood-glucose at time 2.

5.5. Predictive utility of diabetes representations at time 1 and outcome measures at time 2: Logistic regression analyses

In line with the analysis of the time 1 data, to assess the predictive utility of diabetes representations at follow-up, a series of logistic regression analyses was conducted. A similar procedure was therefore employed as at time 1 to determine which of the patients' and partners representations at time 1 prospectively predicted behavioural and psychological outcomes at time 2. To control for clinical and demographic factors relevant variables were entered in the first block in all analyses. These were age, gender, disease duration, years married and BMI and number of prescribed medications for medication adherence. Patients' representations were entered in the second block. Partners' representations were entered in the third block. Finally, past behaviour has been found to be the strongest predictor of future behaviour when it is included in models such as the

theory of planned behaviour (TPB; Ajzen, 1988) and is often seen to have a direct effect on future behaviour over and above the influence of social-cognitive variables (Ajzen, 1991; Oulette & Wood, 1998; Yzer, Siero, & Buunk, 2001). Therefore the regression model was modified by including past behaviour (i.e., exercise adherence at time 1) as an independent variable in the fourth block to examine if it has a direct effect on adherence at time 2. A stepwise procedure was employed to enter each block of variables in the regression model.

Finally, an additional logistic regression analysis was conducted to determine the extent that diabetes representations predicted glucose control. The results of these analyses are displayed in Tables 5.5. and 5.6.

Medication

Patients who believed they had a greater understanding of their illness at time1 (*illness coherence*) were less likely to adhere to medication at time 2 (p <.01). In addition, by entering past behaviour in to the regression equation it is apparent that those adhering well at time 1 were likely to continue doing so at time 2 (p <.05).

Physical activity

Patients with higher BMI scores at time 1 were less likely to engage in physical activity at time 2 (p <.01). In addition, a belief in the importance of *treatment* to avoid *future* complications of diabetes predicted more frequent exercise at time 2 (p <.05). As with medication adherence patients exercising regularly at time 1 were more likely to be doing so at time 2 (p =.001).

Anxiety

Patients with more realistic views (i.e. chronic) regarding the duration of diabetes at time emerged as a predictor of clinically significant levels of anxiety at time 2 ($p < .01$). Patients with greater beliefs in *personal control at* time 1were more anxious at time 2 ($p < .01$). However, patients perceiving greater levels of *illness coherence* were less likely to suffer with anxiety at time 2 ($p < .01$).

Those experiencing more symptoms when blood glucose was high at time 1were nearly 2.5 times more likely to have clinically significant anxiety at time 2 ($p < .01$), whereas those believing that the *cause* of diabetes was due their 'own behaviour' at time 1 were less anxious at time 2 ($p < .01$).

Depression

The level of depression at time 1 was the only significant predictor of depression at time 2 to emerge from the logistic regression analyses ($p < .05$).

Dyadic adjustment

At time 1 patients with stronger *emotional representations* ($p < .05$) and partners' *cyclical time-line* beliefs ($p < .05$) were predictive of lower levels of dyadic adjustment at time 2.

Glucose control

A number of representations of diabetes at time 1 were predictors of levels of HbA1c at time 2. First, patients with a strong belief in an 'external' *cause* of diabetes were in poorer control of their diabetes ($p < .05$). Patients whose partners endorsed a hereditary *cause* of diabetes were in poorer control of their diabetes ($p < .05$). However, patients whose partners held strong beliefs in the importance of

patients' *treatment* to control diabetes *now* were in better control of their diabetes (p <.05).

Table 5.5. Results of logistic regression to examine predictive utility of demographic and diabetes representations at time 1 on behaviour, psychological morbidity and glucose control at time 2

	B	OR	*P*	95% CI
Medication				
Illness coherence	-.158	.854	.004	.766 -.951
Medication (time 1)	.369	1.446	.034	1.028 - 2.033
Physical activity				
BMI	-.124	.833	.009	.804 - .970
Control-future	1.32	1.142	.012	1.030 - 1.265
Exercise (time 1)	.319	1.375	.001	1.146 - 1.650
Anxiety				
Time-line	.235	1.264	.015	1.047 - 1.527
Personal control	.260	1.297	.008	1.040- 1.588
Illness coherence	-.257	.773	.005	.646 - .925
Identity - high bg	.884	2.442	.000	1.639 - 3.579
Cause - 'own behaviour'	-.190	.827	.011	.713 - .958
Depression				
Depression (time 1)	-.266	.766	.047	.589 - .996
Dyadic adjustment				
Emotional representations	-.136	.873	.031	.772 - .987
Time-line cyclical (partner)	-.160	.852	.025	.741 - .980
HbA1c				
Cause-external	.279	1.322	.003	1.103 - 1.585
Control-now (partner)	-.469	.626	.025	.415 - .942
Cause-hereditary (partner)	.577	1.781	.032	1.052 - 3.013

Table 5.6. Results of logistic regression to examine predictive utility of demographic and diabetes representations at time 1 on dietary outcome at time 2.

	B	OR	*P*	95% CI
Starch (g/d)				
BMI	-.235	.790	0.49	.625 - .999
Fibre (g/d)				
Personal control (partner)	.164	1.179	.034	1.012 - 1.373
Emotional reps (partner)	-.148	.862	.030	.754 - .985
Fat (%/d)				
Treatment control (partner)	.173	1.189	.028	1.019 - 1.387
Fat (time 1)	.081	1.084	.008	1.022 - 1.151
Saturated fat (%/d)				
Years cohabiting	.044	1.045	.010	1.012 - 1.078
Control-future	-.091	.913	.054	.832 - 1.002
Carbohydrate (%/d)				
Cause-own behaviour (partner)	.187	1.206	.002	1.074 - 1.354
Carbohydrate (time 1)	.124	1.091	.000	1.064 - 1.206
Sugar (%/d)				
Control-future	.233	1.662	.029	1.024 - 1.555
Cause - 'external'	-.196	.822	.041	.681 - .992
Personal control (partner)	.261	1.298	.017	1.048 - 1.608
Sugar (time 1)	.344	1.411	.000	1.165 - 1.708
Fruit and vegetables (g/d)				
Gender	1.085	2.959	.040	1.049 - 8.347
Time-line (partner)	.174	1.190	.009	1.044 - 1.356
Identity-high bg (partner)	-.262	.769	.031	.606 - .976
Fruit and vegetables (time 1)	.002	1.002	.040	1.000 - 1.003

Starch

Consumption of starch at time 2 was predicted by patients' BMI scores such that patients with higher BMI scores were less likely to consume starchy foods (p <.05). None of the patients or partners scores were predictors of starch intake.

Fibre

A high-fibre diet at time 2 was more likely to be consumed by patients with partners holding a strong belief in their *personal control* of diabetes at time 1 (p <.05). However, partners' beliefs that the patient experiences stronger *emotional representations* regarding the condition at time 1 predicted less fibre intake at time 2 (p <.05).

Fat

Patients with partners expressing stronger *treatment control* beliefs were more likely to consume a higher fat diet. In addition, those consuming more fat at time 1 were more likely to do so at time 2 (p <.01).

Saturated fat

The number of years living with a partner increased the likelihood of consumption of saturated fat at time 2 (p <.01). Patients holding stronger beliefs that the *treatment* for their diabetes would be effective in controlling *future* complications of diabetes predicted less fat intake (p < = .05).

Carbohydrate

Patients whose partner's believed more strongly that the *cause* of diabetes was due to the patients' 'own behaviour' at time 1 were more likely to consume a high

carbohydrate diet at time 2 (p =.01). In addition, those consuming high levels of carbohydrate at time 1 were more likely to continue to do so at time 2 (p =.001).

Sugar

Patients holding stronger beliefs in the importance of the *treatment* to prevent complications of diabetes in the *future* at time 1 were more likely to consume sugar in their diet at time 2 (p <.05). Patients attributing the *cause* of their diabetes 'external' factors were less likely to consume sugar at time 2. However, patients with partners holding stronger *personal control* beliefs were more likely to consume a high sugar diet (p <.05). Finally, patients eating higher levels of sugar at time 1 were more likely to do so at time 2 (p <.001).

Fruit and vegetables

Finally, the gender of the patient predicted the consumption of fruit and vegetables such that females were more likely to consume these items (p <.05).
Higher consumption of fruit and vegetables at time 2 was also observed in patients holding greater *time-line* beliefs at time 1 (p <.01). Finally, patients with partner's reporting a stronger illness *identity* when blood glucose was *high* ate less fruit and vegetables at time 2 (p <.05).

5.6. Summary

The results of diabetes representations at time 1 (Chapter 4) show that representations of both patients and partners were associated with levels of adherence to recommended treatment for diabetes such as medication, physical activity and dietary behaviour. In addition, the impact of such representations on psychological morbidity was assessed and showed that diabetes representations

were also predictive of anxiety and depression in such patients. This chapter examined the extent to which diabetes representations are stable over a 12-month period and the differences between patients' and partners' representations at follow-up. Furthermore, the extent to which these representations prospectively predicted adherence and control of diabetes was also examined, after controlling for previous levels of adherence. Achieving a good follow-up response rate of over 80% has enabled comparisons of diabetes representations at both time-points to be made with a good degree of confidence and these are examined further below.

Stability of diabetes representations and outcome variables

By assessing diabetes representations at 12 months it has been demonstrated that, at least in the present sample, that some dimensions are not stable over time. This was true for both patients and partners, such that the direction of change in partners' representations was the same as for the patient. This was true also for most dimensions except *consequences* (which decreased for patients) and a belief in 'own behaviour' as a *cause* of diabetes (which increased for partners). In addition, differences between patients' and partners' representations at time 2 were evident for only two dimensions and did not replicate differences at time 1. These differences existed for the perceived importance of *treatment* for diabetes for controlling the condition *now* (partners had stronger beliefs) and beliefs that the 'own behaviour ' of patients was a *cause* of diabetes (partners held stronger beliefs). Thus, as there were few differences at both time-points it may be concluded that patients and partners share similar representations of diabetes but that their representations are subject to change over time. It also cannot be determined which party of the dyad influences the other; do patients' beliefs guide the partner or vice-versa?

It was interesting to note that while *identity* scores remained stable at time 2, dimensions pertaining to the *control* of diabetes changed at time 2 reflecting a less optimistic or positive view of diabetes. In addition, patients' emotional responses to having diabetes increased such that they perceived more fear, anxiety etc with regard to their diabetes over the follow-up period. Such findings suggest that beliefs regarding the control of diabetes and the emotional impact of the disease may operate independently of the extent of symptoms experienced by patients living with diabetes.

Both patients' and partners' representations of *personal control* and *treatment control* significantly decreased at time 2. In addition, patients' beliefs in *consequences* of diabetes and patients' belief in the importance of *treatment* to control diabetes *now* and to avoid complications in the *future* decreased at time 2. However, reductions in these beliefs did not appear to result in reduced levels of adherence to either medication or exercise (in fact, exercise levels increased). In addition, levels of adherence to diet remained stable for consumption of fats, sugars and fruit and vegetables, however, there was a reduction in starch and fibre (diabetes patients are recommended to eat a diet high in starch and fibre). Thus, this varied pattern of adherence suggests that it is aspects of the dietary regime that patients find most difficult to follow. It is suggested that patients may find it difficult to sustain positive changes in their food consumption.

The predictive utility of illness representations

The application of logistic regression analyses to test the predictive utility of time 1 diabetes representations with behavioural and psychological outcomes at time 2 did not confirm the results from the cross-sectional analyses at time 1. The addition of 'past behaviour' in the equations and the reduced sample size at time 2 may partly explain these results.

Although consistency could not be found between the two time-points there are some results worthy of mention with regard to adherence. With regard to psychological morbidity, perceived *identity* when blood-glucose was *high* was inversely associated with anxiety at time 1 but at time 2 the direction of the relationship was positive suggesting that the symptoms of high blood-glucose increase levels of anxiety over time.

At time 2 adherence to medication was less likely to be executed by patients with a greater understanding of diabetes. It is possible that patients with a greater understanding of the condition are more adept at controlling their glucose levels by manipulating their diets and levels of physical activity and are thus less reliant on taking oral agents to manage their condition.

Physical activity, however, was less likely to be undertaken by those with greater body mass and more likely to be undertaken by patients with stronger beliefs in the importance of *treatment* for avoiding complications in the *future*. For dietary behaviour logistic regression analyses demonstrated a number of pertinent findings. First, patients' belief that *treatment* will be effective in avoiding complications of diabetes in the *future* predicted less intake of saturated fat in their diet whereas this representation predicted greater sugar intake. However, patients' beliefs in an 'external' *cause* of their diabetes predicted lower sugar intake.

At time 2 partners representations were more ubiquitous than those of patients in predicting outcomes. First, higher fibre intake was predicted by partners' perceived *personal control* of the condition. However, partners' holding greater beliefs that the condition has an emotional impact on the patient predicted less fibre intake. Partners' representations of diabetes also predicted intake of dietary fat such that *treatment control* beliefs predicted higher fat intake in patients. In addition, the duration of living with a partner increased the likelihood of saturated fat intake suggesting that higher fat diets result from longer relationships. Greater

partner beliefs in the chronicity of diabetes enhanced patients' consumption of fruit and vegetables whereas partners perceiving that the patient experiences more symptoms (*identity*) when blood glucose was *high* predicted less vegetable consumption. Finally, with regard to the *cause* of diabetes, partners' beliefs that the patients' 'own behaviour' was instrumental predicted greater consumption of carbohydrates. In conclusion, it appears that partners' representations of the patients' condition are important with regard to the role they play in patients' management of their diabetes.

CHAPTER 6: DISCUSSION

6.1. Introduction

The first two chapters of this thesis reviewed the literature relevant to the present research examining the role of significant others in the health behaviours of patients with diabetes. In Chapter 1, the importance of the social context in managing diabetes was addressed and Chapter 2 examined the predictive utility of the illness representations framework in a range of outcomes in patients with chronic disease including diabetes. Particular attention was given to the importance and validity of assessing the illness representations of significant others and their relationship with patient's adaptation in chronic disease.

This final chapter of the thesis discusses the findings of the research in the context of previous work and arising methodological issues. As the results of analyses conducted at both time-points are summarised in Chapters 4 and 5 respectively they are not revisited in detail in the following discussion. The discussion, does, however, give consideration to the study sample, analysis of data and the findings in the context of the primary aims of the study; the assessment of diabetes representations of patients and partners, differences between patient and partner representations and the predictive utility diabetes representations with regard to the behavioural and psychological outcome variables.

The discussion then proceeds with a critique of the selected measures of diabetes management (described in Chapter 3) and offers suggestions for improving the measurement of these outcomes. In addition, of relevance to the literature reviewed in Chapter 1, the relationship between dyadic adjustment and social support in the context of patient-partner representations of diabetes is addressed. Finally, the cumulative findings accrued from the systematic review of the illness representations literature (Chapter 2) and the present research have implications

for future work. Indeed, the findings are considered to be particularly pertinent in the guidance and direction of behavioural interventions aimed at improving the self-management of diabetes.

6.2. Study sample

First, the generalisability of the results are supported by the attainment of a good sample size (n=164 dyads) recruited from 35 geographically diverse primary care surgeries. It is also reiterated that many of the patients approached for the study had participated extensively in the Somerset and Avon Survey of Health (SASH). This ongoing cohort study of chronic disease was in operation for some 10 years previous to the commencement of the present project. Therefore to attain a response rate of 44% in a postal questionnaire survey in this context is considered particularly good considering that consent was also sought from patients' partners.

There are, however, some limitations relating to the sample. First, the extent of previous participation implies that the recruited sample were 'self-selected' and such attention received in the interests of research does not make them typical patients. Secondly, although the mean age of 67 years reflects the expected age range for the onset of the disease such an aged sample were suffering from a variety of co-morbid conditions that may have affected the measurement of diabetes-specific representations and outcomes. A final point is that patients from ethnic backgrounds may have been underrepresented. This is an important issue considering the reported increased prevalence of diabetes in Black and Asian populations (Abate & Chandalia, 2003; Tong & Cockram, 2003).

The implications of sampling limitations

The methodological and sampling limitations described have implications for the generalisability and meaning of the findings for patients with type 2 diabetes in the

general population. The fact that many of the participants were long-standing participants in SASH demonstrates that such patients are, by character, more interested in their illness and its management. Additionally, by receiving feedback from involvement in previous aspects of the SASH study it is possible that these patients have a greater awareness of the issues that go hand in hand with living with a chronic disease. Therefore, it must be considered that these 'primed' and motivated individuals are, to some extent, better managed patients whereas patients demonstrating poorer management of their diabetes would be less forthcoming to participate in research of this nature. Indeed, the findings based on the present participants may not necessarily have commonality with results obtained from 'naïve' research' participants.

The extent of comorbidity reported by patients makes it difficult to delineate the extent that responses to the illness representations questionnaire provide an accurate insight of living with diabetes. For example, rheumatoid arthritis may be more debilitating than well-managed diabetes in terms of its impact on lifestyle which, in turn, may be related to levels of psychological morbidity. Although, the illness representations measures were specifically worded for diabetes patients, outcome measures such as the HADS provide a global indication of psychological morbidity rather than being disease specific.

Finally, despite recruiting patients from a variety of geographically diverse GP surgeries such a procedure did not yield a fair representation of ethnic minorities. Therefore, it is not possible to state to what extent the diabetes representations of Black and Asian patients are similar to those of White-European patients and whether they are similarly predictive of outcomes. However, the participation rate of ethnic minorities in the present study was not dissimilar to recruitment rates found in previous studies undertaken within SASH.

Overall, the issues outlined above may prove to be more salient in the event of the development of interventions aimed at improving the self-management behaviours of patients with type 2 diabetes. At present, it is premature to assume that all patients with type 2 diabetes share similar representations and engage in health behaviours equally despite of their management, disease and ethnic status.

6.3. Analysis of data

Treatment of patient and partner data

A primary aim of this thesis was to examine the relationship between the illness representations of patients with type 2 diabetes and their partners to determine the extent of dissimilarity between each party. Previous studies examining the influence of illness representations of significant others in chronic disease have focused on the extent of dissimilarity between patients and significant others by calculating 'difference' scores (i.e., Heijmans et al, 1999, Figueiras & Weinman, 2003; Urquhart-Law, 2002). However, in these studies, the differences in patients' and partners' representations have not been calculated consistently (the methods are described in Chapter 2). At present, therefore, there is no consensus on how to best approach this relatively new area of enquiry in the illness representations literature. Furthermore, as the focus of the present thesis was explore the relative influence of partners' representations on patients' health behaviours, examination of the degree of dissimilarity was not considered the most appropriate approach. This view is supported by t-test analyses which demonstrated that patients and partners were in considerable agreement with regard to the dimensions measured. In view of these considerations a decision was made not to gauge the magnitude of the difference in representations. Instead, absolute values were used to evaluate the influence of partner representations and to determine if they make an independent contribution to patients' self-management behaviours and psychological outcomes. As many of the outcome variables of interest were extremely skewed, (i.e.,

medication, physical activity, anxiety, and some dietary components), analyses were restricted to methods accommodating binary outcomes, namely binary logistic regression.

The partners' representations were entered after patients' representations in the logistic regression model in order to determine the strength of their influence on patients' self-management behaviours. The results revealed that a number of partners' representations were significant independent predictors of dietary outcomes, glucose control, psychological morbidity and dyadic adjustment. The robustness of the findings are demonstrated with the narrow 95% confidence intervals which did not cross 1 for each significant relationship.

Entry of variables into regression model

There is no evidence from past work to suggest a logical order for the entry of the independent variables (diabetes representations) in the logistic regression modelling. Therefore, stepwise entry of the independent variables was chosen in favour of hierarchical entry. This decision was supported by the absence of strong theoretical reasoning for entry of the diabetes representations and the exploratory research aims - in such circumstances a stepwise procedure is considered to be justified (Field, 2000). Additionally, the schematic nature of the illness representations framework suggests that each dimension may play an equally important role in predicting outcomes thus negating any priority of entry. Therefore, the entry of diabetes representations into the model was decided on the statistical strength of the correlation with the outcome of interest. The stepwise procedure also served to reduce the number of variables entered at each step increasing the statistical power of the model.

Justification for logistic regression analyses

It is acknowledged that logarithmic transformations could have been performed to 'normalise' the variables assuming a skewed distribution. This approach would have made linear regression techniques possible to predict the outcomes of interest as continuous rather than discrete variables. It is also acknowledged that by splitting the outcome variables at the median (medication, physical activity, marital satisfaction) or recommended values/ cut offs (diet, psychological morbidity) to permit the use of logistic regression analyses prohibits the range of variance in the self-reported behaviours and other outcomes to be accounted for in the regression equations. Indeed, to some extent, splitting the outcome data for binary analysis limits the extent that the selected outcome measures are informative of patients ' behaviours.

Despite these considerations, a decision was made to employ logistic regression analyses for binary outcomes. Several theoretical and practical considerations led to the application of logistic regression procedures.

First, the extreme skewness of the distribution of scores for medication, exercise, anxiety and some dietary components suggested it would be appropriate to compute binary outcomes for these variables. Indeed, in nearly all cases recommended or clinically recognised cut-offs are available, and thus, where possible, the outcome data were split according to these recommended/recognised cut-offs.

Second, a further advantage of the logistic regression approach is that it makes no restrictive assumptions about the distribution of the independent variables and their relationships with the dependent variables; i.e., they do not have to be normally distributed, linearly related or of equal variance within each group (Howell, 2002). Thus, the logistic regression approach permits the inclusion

of both categorical and continuous independent variables. For the present study this enabled the inclusion of both categorical variables (e.g., gender) and continuous variables (e.g., disease duration, years married etc.).

Third, with regard to ease of interpretation, the calculation of odds ratios provides an intuitive index to assess the likelihood that an individual will engage in a particular behaviour. This is considered to be advantageous in comparison to interpreting the percentage of explained variance that is the norm in the interpretation of linear regression methods.

Justification for splitting outcome variables for binary logistic regression

As previously reported a number of outcome variables were clearly skewed as shown in the figures in Chapter 4. The justification for splitting the outcome variables is described below:

In the case of medication adherence, scale scores ranged from 9 to 30 (complete adherence). however, the distribution of the data revealed that 80% of patients scored 29 or above on this scale. The extremely skewed nature of this distribution suggested that it would be appropriate to treat this variable as a binary measure. indeed, this approach is not without precedent. in some other chronic diseases, such as HIV, medication adherence is often treated as a binary outcome e.g., patients whose adherence is at 80% or greater are considered to be adherent, whereas all others are deemed non-adherent (Singh et al., 1996).

With regard to levels of physical activity, the data demonstrated that 72% of patients reported engaging in low intensity exercise. such low levels of activity is consistent with previous investigations (Ford & Herman, 1995; Hays & Clark, 1999) suggesting that this is a 'real' behavioural feature of diabetic patients

and not due to sampling error. Thus, once again, the highly skewed nature of the data advocated the treatment of the variable as a binary outcome.

Although there are recommendations for physical activity which are aimed at the general population, the fact that the majority of patients in this study were not attaining even the minimum requirement (i.e., at least 30 minutes on at least 5 days of the week, at a moderate intensity). It was therefore deemed appropriate and realistic to split the data according to the median of the study population.

The distribution of the dietary data also revealed that some of the outcome measures were not normally distributed. In order to be consistent in the treatment of all the dietary outcomes, and also to achieve consistency in the overall analytic approach, it was decided that all the dietary measures should be treated as binary variables. Furthermore, the dietary recommendations given to people with diabetes are the same as those given to the wider population. Consequently, the dietary data were split according to these recommendations and not the median scores for the study population.

Pychological morbidity was assessed with the HADS. It was clear that, although depression assumed a normal distribution, scores for anxiety were skewed towards higher levels of morbidity. As clinically significant disorders are identified by scores greater than 11 on the HADS the scores for anxiety and depression were split at this value.

Finally, the marital satisfaction variable was also treated as a binary outcome in order to be consistent with the analytic approach adopted for all other outcome measures. However, as normative data for this scale do not exist for patients with diabetes, the data were split at the median for the study population.

6.4 Illness representations of patients with type 2 diabetes and their partners

Plausibility of diabetes representations

Examination of the mean scores in relation to the highest attainable score for each of the illness representation sub-scales revealed that, in general, patients and their partners had developed representations about the illness that were generally in accordance with conventional medical views and understanding of type 2 diabetes. In addition, such representations were consistent with the results of other work (Barnes et al, in submission). For example, patients and partners who held strong beliefs in a chronic *time-line,* believed the *consequences* to be serious, and believed they had a high degree of *illness coherence* or understanding of the condition. In addition, dyads demonstrated strong beliefs in the efficacy of the treatment for diabetes (*treatment control)* and the importance of *treatment* to control diabetes *now* and to avoid *future* complications of diabetes. Finally, the scales derived from the principal components analysis of causal attributions demonstrated that 'own behaviour' was more salient than 'external' factors as a cause of diabetes. In general, this configuration of diabetes representations demonstrates a high level of awareness of the nature of diabetes and its treatment for patients and partners. Such beliefs may have been formulated through living with the disease for a number of years (mean=9 years). Finally, with regard to illness *identity,* patients and partners reported relatively few symptoms as a result of either *low* or *high* blood-glucose.

Reliability of diabetes representations

The internal reliability of both patients' and partners' diabetes representation scales were good. However, scale reliability was not as satisfactory as those reported by Moss-Morris et al (2002) in the development of the IPQ-R using patients from 8 disease groups. Nonetheless, reliability coefficients above 0.60 are considered acceptable, particularly if scales consist of less than 10 items and there

is a good theoretical basis for the scale (Loewenthal, 1996). For patients, alpha coefficients ranged from 0.60 to 0.84 and are favourable compared with illness representation scales utilised in other diabetic populations (Lawson et al, 2004; Cartwright & Lamb, in submission). The partners' scales ranged from 0.54 to 0.81 although, at present, there are no reported internal reliability data on partners' representations of diabetes. The partners' scales did, however, compare favourably with scales assessed in partners of non-diabetic patients (i.e, Heijmans et al, 1999; Figueiras & Weinman, 2003; Helder et al, 2002b, Barrowclough et al, 2001). Although small improvements could have been made (less than 0.5 in each case) to the scales of patients and partners by removing poorly correlated items a decision was made to keep them in their original form for reasons of consistency in assessing the stability of the dimensions at time 2 and for comparisons with patients' representations.

The observation that the alpha coefficients may be considered low for some dimensions does, however, have implications for the interpretation of results and for broader illness representations theory. For example, patients' *time-line* dimensions (acute and cyclical) were not as reliable as the scales for partners suggesting that partners have more coherent views regarding the temporal perception of the patients' diabetes. In addition, the dimensions of *consequences* and *personal control* yielded low alpha coefficients and this was particularly true for partners (0.58 and 0.54 respectively). This may reflect wide variations in the perceived seriousness of the disease and its implications for the patient and the extent of the patients' efficacy in controlling the condition. Further work in the context of partner representations are required to determine if the reliability of these scales can be improved in alternative populations.

Finally, it was interesting to note that the highest alpha coefficients were found (for patients and partners) for the additional IPQ-R dimensions *illness coherence* and *emotional representations* and the additional control scales adapted from the PMDI.

Such reliability provides good theoretical justification for their inclusion in further work of this nature.

In accordance with Weinman et al (1996) and Moss-Morris et al (2002) the individual causal items were factor analysed using principal component analyses and the resulting factors collectively explained a large percentage of the total variance. This procedure led to the development of two scales for both patients and partners reflecting theoretically coherent categories. Indeed, the scales made a distinction between 'internal' and 'external' causal beliefs and each yielded good internal reliability. The procedure also permitted hereditary factors to be utilised as a single item variable. No significant differences were found between patients and partners for all three scales. The scales did, however, prove to be independent predictors of outcome at both time-points. Finally, the scales derived for causal factors were broadly similar to scales operationalised by Cartwright and Lamb in patients with type 2 diabetes (in submission) thus providing further evidence for the utilisation of such scales in the present thesis.

Inter-correlations between diabetes representations

The correlation matrix shown in Chapter 4 demonstrated that a number of diabetes representations were significantly and positively correlated.
Due to the schematic nature of the illness representations framework it is expected that logical relationships between representations would exist. Indeed, Heijmans (1998) asserts that illness representations should be conceptualised as groups of beliefs or schemata rather than single cognitions. In the present study, broadly similar inter-correlations have been reported to that of previous studies describing the development of the IPQ (Weinman et al, 1996) and IPQ-R (Moss-Morris et al, 2002). For example, *illness coherence* was strongly correlated with *treatment control* and *consequences* was strongly correlated with *emotional representations.*

Nonetheless, Field (2000) suggests that correlation coefficients exceeding 0.80 or 0.90 may be indicative of multicollinearity which may cause bias in regression models. However, the only inter-correlation found to exceed 0.60 was between beliefs in the importance of *treatment* to control diabetes *now* and to avoid complications in the *future* ($r = .801$, $p < .01$). The extent that these representations were correlated is considered logical as individuals who believe the treatment to be important for controlling diabetes would also be likely to believe that the treatment would help to prevent future complications relating to diabetes.

6.5. Differences between patients and partners representations of diabetes

The results at time 1 (Chapter 4) demonstrated that patients and partners are largely in agreement with regard to representations of diabetes. For only 3 of the 14 diabetes-specific dimensions were differences found at time 1, namely *personal control, illness coherence,* and the importance of *treatment* to avoid *future* complications of diabetes. Interestingly, partners held weaker beliefs than the patient regarding the patients' personal beliefs in controlling diabetes but exhibited stronger beliefs that the patients' treatment would be effective in avoiding the complications associated with the disease. Partners also had a greater perception of the degree of understanding the patient had of their condition. The differences observed between the patients' and partners' representations were not replicated at follow-up at time 2 where partners held stronger beliefs than patients that *treatment* could control diabetes *now* and that the patients' 'own behaviour' was a *cause* of diabetes. The differences found between patients' and partners' representations at both time-points did not yield any consistency with the findings of Urquhart Law (2002) examining dissimilarity between mothers and adolescents representations of diabetes assessed with the IPQ-R. In this study differences were only found for *consequences* and *emotional representations,* for which mothers scored more highly. Such inconsistency regarding the dissimilarity of representations within and between studies makes meaningful interpretation difficult. However, it

is clear from the results of both studies that 'significant others' generally hold similar diabetes representations to those of the patient.

Finally, it is reiterated that, in the present study, patients and partners were requested to complete the study measures independently. However, by conducting the project via postal survey methods it must be acknowledged that patients and partners may not have completed their respective questionnaires without conversing with their partners.

Minimisation and maximisation of illness representations

In relation to the mean scores derived for patients' and partners' representations of diabetes (Table 4.6) there are implications with reference to the extent that partners' 'minimise' or 'maximise' their views of the patients' experience of illness. According to Thompson and Pitts (1992) (see Chapter 2), expression of 'maximisation' or overprotective behaviour by the spouse may have a negative effect on patients' well-being. For example, partners may view the *consequences* of living with diabetes as not as serious as the patients' views, which is expressed as problem 'minimisation'. Conversely, partners may view the *consequences* of an illness as far more serious than does the patient and is expressed as problem 'maximisation'. The effect of 'maximisation' may lead to overprotective behaviour on the part of the spouse leaving the patient playing a more passive role in adjusting to and managing their disease. The present results suggest that patients and partners share a high level of agreement regarding their beliefs about diabetes. However, differences were found on three dimensions of diabetes representations at time 1 and it is feasible these discrepancies could be interpreted in this way. For example, partners 'minimised' *personal control* beliefs and 'maximised' representations of *illness coherence* and the extent that *treatment* was important for avoiding complications of diabetes in the *future*.

The expression of 'minimisation' and 'maximisation' of these variables measured at time 1 appeared to have implications in the extent that partners' *control* and *treatment* beliefs were predictive of aspects of patients' self-management behaviour at time 2. Indeed, the present results suggest that some aspects of 'minimisation' and 'maximisation' may or may not be beneficial for patients in terms of patients' self-management behaviours. It is demonstrated that patients with partners who 'minimised' *personal control* beliefs at time 1 were more likely to consume a greater percentage of sugar in their diet at time 2. Whereas, patients with partners 'maximising' the importance of *treatment* to avoid complications of diabetes in the *future* were more likely to reduce the intake of saturated fat at time 2. Thus, in this case, partners' 'minimisation' of *personal control* beliefs appear to have a negative effect and 'maximisation' of treatment beliefs appear to have a positive effect in terms of patients dietary intakes.

It is considered that such results may have implications for interventions aimed at manipulating illness representations with a view to improving health behaviours. Indeed, partners of patients 'maximising' or 'minimising' aspects of the patients' experience of the disease could receive counselling with the aim of eliciting more positive appraisals of the patients' illness. In turn, such appraisals may lead to more favourable behaviours and outcomes.

Findings at follow-up

At 12 months only 18% of dyads were lost to follow-up (n=134) and the majority (76%) of patients consented to give blood to assess their blood-glucose levels. The diabetes representations of patient-partner dyads measured at time 1 were also measured at time 2. No differences were found between demographic and clinical characteristics of dyads completing questionnaires at time 1 only compared with those assessed at both time-points. Significant differences were, however, found regarding representations of diabetes. Patients' assessed at both time-points

perceived lower levels of *illness coherence* and held stronger beliefs that the *cause* of their diabetes was 'hereditary'. Partners assessed at both time-points exhibited stronger beliefs in the extent of the patients' *personal control* of their diabetes.

6.6. Predictive utility of diabetes representations

Stability of illness representations

The systematic review of illness representations in Chapter 2 demonstrated a lack of data relating to the stability of illness representations in chronic disease over time. This issue was examined in the present study by examining the extent that diabetes representations were stable over time (i.e., representations at time 1 compared with time 2). It was apparent that mean scores for a number of dimensions increased or decreased significantly between time 1 and time 2 and this was as true for patients as partners. Some differences were also found between patient and partner scores at time 2 such that partners held stronger beliefs than patients in the importance of *treatment* to control diabetes *now* and held stronger beliefs that the patients' 'own behaviour' was a *cause* of diabetes. In the present study changes occurred for patients and partners over the study period of 12 months. It is, therefore, reiterated that, patients and partners are living with a disease that is not only chronic but is long-standing. Participants' had been living with the disease for many years. Thus, it may not be considered surprising that patients were still experiencing changes in their beliefs about diabetes over time. An explanation for the observed changes may be found in the way an individual appraises their responses to diabetes. It is reiterated that the SRM conceptualises health related decisions as being dynamic rather than static. Thus, a patient (or partner) may evaluate the efficacy of a particular health behaviour - if that behaviour is appraised as being ineffective, the patient may in turn, choose an alternative strategy or may modify their representation of the illness. The

appraisal of coping responses and health behaviours is a neglected 'stage' of the SRM which may have implications for disease related behaviours and outcomes.

It is considered that the neglect of the assessment of appraisals of patients' coping efforts is partly due to conceptual difficulties with regard to measurement and a lack of longitudinal data. Weinman (2003), however, speculates that the addition of the *illness coherence* dimension to the framework provides insight into appraisal processes. For example, if the illness makes sense to the patient then it is likely that coping efforts (including treatment adherence) are working accordingly the measure of *illness coherence* could also be a marker for treatment efficacy.

The meaning of partners' representations in managing diabetes

A number of partners' representations were predictive of self-management behaviours. At time 1 partners' belief in personal control of the condition predicted a greater intake of dietary fibre and partners' beliefs in treatment control predicted less consumption of carbohydrates. Such results indicate that partners' representations of the control of diabetes are communicated to the patient and appear to be important with regard to the extent they influence these aspects of dietary behaviour.

Interestingly, at time 2 the impact of partners' representations were more prevalent in predicting outcomes than representations observed at time 1. Partners' beliefs appeared to be most predictive of behavioural outcomes such as physical activity and dietary choices rather than the degree of psychological morbidity and marital satisfaction. Additionally, poor blood-glucose control was influenced by partners' beliefs regarding 'hereditary' factors as a cause of diabetes. Thus partners' holding stronger beliefs that diabetes is 'hereditary' with regard to cause may communicate to the patient a belief that the onset of diabetes was inevitable and not a direct result of the patients' lifestyle and that there was little the patient could do in terms

of managing the condition. Therefore, such beliefs may serve to excuse the patient from taking responsibility for his/her disease. It is suggested that this may, in turn, be detrimental to recommended management behaviours resulting in poorer glucose control. Conversely, better glucose control was influenced by partners' beliefs in the importance of treatment to control diabetes now. Thus patients with partners who communicate the belief that the recommended treatment is important and effective for controlling the disease are more likely to engage in management behaviours that are beneficial for attaining lower blood-glucose levels.

Consistent with the results at time 1, it was evident that partners' beliefs in the patients' ability to control their diabetes predicted a higher intake of fibre. Thus, it is possible that partners may help to reinforce patients' self-efficacy beliefs (i.e., believing that the patient has the ability to perform this important aspect of the dietary regime). However, partners' personal control beliefs predicted greater sugar consumption by patients. It appears that, although the partner believes the patient can control their diabetes, this belief has both a positive and negative influence on dietary outcomes.

In addition, partners' beliefs in *treatment control* predicted greater intake of non-saturated fats. This result could be interpreted as being a positive outcome in that dietary advice for diabetes patients encourages the use of mono-unsaturated fats (e.g. olive oil) and poly-unsaturated fats (e.g. sunflower oil) rather than saturated (animal/dairy) fats (these 'healthy' fats are believed to play a role in reducing cholesterol levels). Finally, partners' beliefs that the *cause* of diabetes is due to the patients' 'own behaviour' predicted greater carbohydrate consumption and partners with more realistic perceptions of the duration of the disease (i.e. chronic) predicted greater fruit and vegetables consumption. These results are consistent with the assumptions that partners' beliefs will have on patients' behaviour.

As some findings appear to be inconsistent with regard to better management of diabetes it is suggested that although partners' believe that the patient has the ability control their condition effectively the patient may elect to continue with aspects of dietary behaviour that are detrimental to good self-management. This is an indication that patients retain a degree of autonomy or 'ownership' over their condition and its control. Indeed, it might be an unrealistic expectation for partners' representations of diabetes to consistently predict health behaviours that will favour better blood-glucose control. However, in general, patients appear to benefit from partners that hold favourable views that the diabetic treatment regimen will have a positive effect on the course of the disease. It is concluded, therefore, that partners' beliefs can have a positive impact on patients' management of diabetes by influencing behaviour that would favour better management of the disease and enhance glucose control. However, despite demonstrating that partners' beliefs play an important role in behaviours and glucose control, it cannot be determined which party of the dyad influences the other with regard to the origins of diabetes representations. Do patients' beliefs guide the partner or do the partners' beliefs guide the patient in their beliefs?

Differences in predictive utility of diabetes representations at time 1 and time 2

The time 1 representations were also used in logistic regression analyses to predict health behaviours measured 12-14 months later. However, the results of these analyses shared little commonality with the results of the time 1 analyses despite identifying many significant predictors of behaviour. This phenomenon may be partly explained by the addition of past behaviour in the analysis which was a significant predictor of many outcome variables. In addition, the reduced sample size at time 2 may have influenced the extent of behavioural outcomes.

Not only were changes in diabetes representations evident at time 2, there were also changes in the behavioural and psychological outcome variables that were assessed at time 2. Thus, although the time 1 diabetes representations were used to predict behaviour prospectively at time 2, the inconsistent findings may be due to changes in the outcome variables of interest. Another explanation is the addition of past behaviour in the regression model (adherence assessed at time 1) to control for the extent that patients' adhered to the self-management behaviours in the past. By including behaviour at time 1 as a variable in the analyses it has shown that past behaviour does indeed have a direct effect on behaviours at time 2 in addition to patient and partner representations (this was the case for medication, exercise, consumption of fats, and sugars). In studies utilising Protection Motivation Theory (PMT; Rogers 1983) past adherence behaviour has been shown to have a direct effect on future behaviour in the prediction of a range of behaviours including adherence with eye patching (Norman et al, 2003, Searle et al, 2002) and breast self-examination (Hodgkins & Orbell, 1998). According to Ajzen (1988) past behaviour influences people's beliefs about the behaviour and it is these beliefs that determine subsequent behaviour. It has been argued that past behaviour is a behavioural proxy for self-efficacy (belief in personal control) such that by adequately engaging in a given behaviour, participants are reinforcing the belief that they are capable of performing that behaviour and continue to do so (Searle et al, 2002). A further point with regard to the purported dynamic nature of health behaviours in the context of the SRM is the possibility that the prediction of health behaviours is the result of 're-appraisal' of given behaviours over the study period. Indeed, it is likely that adherence levels fluctuate according to their perceived efficacy at a given time.

Usefulness of additional illness representation dimensions

The additional illness representation scales pertaining to the IPQ-R (*treatment control, cyclical-timeline, illness coherence* and *emotional representations*) and scales adapted from the PMDI (importance of *treatment* to control diabetes *now* and to avoid complications in the *future identity* and the *identity* scales) were shown to be useful with regard to their predictive utility. Indeed, at time 1 these dimensions dominated the outcome of the logistic regression analyses whereas only the *personal control* scale from the original IPQ was a predictor of medication. However, this leaves the question to what extent the original IPQ scales could predict outcomes if entered in the regression model alone? Indeed, the breadth of representations measured in the study that were subsequently associated with outcomes challenges the assertions of Leventhal and colleagues (1984) that individuals perceive their illness in the context of 5 'core' dimensions. The extension to the *control* dimension undertaken with the adaptation of the scales derived from the PMDI (importance of *treatment* to control diabetes-*now* and to avoid *future* complications) demonstrated high internal reliability in addition to yielding very high mean scores. Such beliefs in the importance of treatment were also positively associated with health behaviours. The findings relating to these dimensions serve to validate their inclusion in the study. There is, however, no theoretical reason restricting the number of dimensions operationalised in future research. Indeed, it may be of more value to select dimensions in accordance to the disease of interest and informed by the accumulated evidence of past research. Nonetheless, the present results have demonstrated that scales taken from the IPQ, IPQ-R, PMDI and factor analysed causal attributions were all predictors of either behaviour or psychological outcomes in patients with type 2 diabetes.

6.7. Relevance of findings to previous research

Overall, there was little consistency with regard to the predictive utility of diabetes representations with previous studies outlined in the review of literature in

Chapter 2. The predictive utility of the dimensions adapted from the PMDI measuring the importance of *treatment* to control diabetes *now* and to avoid *future* complications were more common in terms of predicting health behaviours than dimensions of the IPQ-R. This was true for both patients' and partners' representations and at both time-points. First, at time 1 patients' beliefs in the importance of *treatment* to control diabetes *now* were associated with better medication adherence. Partners' beliefs in the importance of *treatment now*, however, were associated with less fruit and vegetable consumption by patients at time 1 (and therefore not beneficial to the patient). At time 2, patients' beliefs in the importance of *treatment* to avoid *future* complications were associated with higher levels of exercise whereas partners' scores for this dimension were associated with greater sugar intake by patients. It appears that although patients' perceptions of these dimensions as are predictors of positive outcomes in terms of management behaviours, partners' perceptions do not necessarily result in positive patient outcomes. Nonetheless, partners' beliefs in the importance of *treatment* to control diabetes *now* was associated with lower HbA1c scores in patients. The predictive utility of patients' perceptions of these dimensions is not surprising as the systematic review in Chapter 2 demonstrated that the equivalent construct (*treatment effectiveness)* was a consistent predictor of self-management behaviours in diabetes patients. For example, dietary behaviour was predicted by *treatment effectiveness* and *seriousness* (the combined variable of time-line and consequences) in three studies (Hampson et al, 1990, Glasgow et al, 1997; Skinner et al, 2002). Such findings suggest that patients' representations regarding the importance of the recommended treatment for diabetes and the perceived severity of the condition are the most important predictors of these behaviours. The consistency of the results may be explained in part by the fact that these studies were undertaken with the complete PMDI variables by members of the same team, using variations of a global outcome measure, (i.e., the Summary of Diabetes Self-Care Activities Scale; Glasgow et al, 1997; Hampson et al, 1990; 1995, Skinner et al, 2002). In contrast, studies employing the IPQ and IPQ-R showed that only *control*

beliefs were predictors of self-management behaviours (Griva et al, 2000, Watkins et al, 2000), whereas Cartwright and Lamb (in submission) found no significant correlations between IPQ dimensions and adherence to dietary recommendations in patients with type 1 or type 2 diabetes.

However, in the present study the operationalisation of the *control* dimensions of the IPQ-R for patients and partners' was not as productive with regard to predicting patients' behaviours. A possible explanation for this is that the *control* dimensions of the IPQ-R were not rated as highly by patients and partners as the PMDI scales and were also less reliable in terms of their internal consistency. Differences in responses to these dimensions may be a function of the specificity of the items to diabetes and the impact the disease has on a patient's life. Evidence to support this contention comes from Lawson et al (in press) who examined the comparative predictive utility of the IPQ and PMDI in the care seeking behaviour of patients with type 1 diabetes. It was shown that the *treatment effectiveness* dimension from the PMDI and the *control* dimension from the IPQ were the only positive predictors of clinic attendance. In order to better understand these results the authors examined the wording of items in each instrument. They reported that the IPQ items relate to present and past effects of diabetes whereas the PMDI items focus more on the current impact of diabetes. This has implications for future research as a diagnosis of diabetes may have had a detrimental impact on patients' lives in the past but any difficulties arising from the illness may have been resolved and have little effect on current lifestyle. This may be particularly pertinent in the present sample as the majority of the patients have had the disease for many years.

6.8. Critique of behavioural outcome measures

One of the strengths of the present study is the employment of individual behaviour-specific measures of diet, physical activity and medication. It was thus anticipated that the selection of such measures would provide a comprehensive

evaluation of the magnitude and nature of the relationship between diabetes representations and measurement of these important and diverse behaviours central to the management of the disease. Although the measures have provided a useful insight into the extent that the participants were engaging in the relevant health behaviours there are number of methodological issues that are addressed in the following paragraphs.

Dietary assessment

As far as it is known this is the first study to assess the individual components of diet in the context of their relationship with illness representations. The balance of dietary components is particularly important in such patients and therefore to attempt to evaluate dietary behaviour in this way is a particularly informative approach in diabetes research. The food frequency questionnaire (HEA 3, Little et al., 1999; 2000) was developed as an assessment tool for the evaluation of risk of MI in the context of primary care. The measure has also been shown to perform as well as the accepted standard reference, a seven-day weighed record (Little et al., 2000). However, a particular concern in relation to dietary assessment in the present study was the extent of 'low energy reporters' (73%-75%) identified in the sample. It is clear that patients underreported or underestimated their energy intake, this may have been due to biases of retrospective recall. Retrospective recall may have been a particular problem with regard to the age of participants and long-term cognitive decline has been associated with a diagnosis of type 2 diabetes (Elias et al., 1997; Scott et al., 1998). Nonetheless, patients did demonstrate a degree of consistency in relation to energy intake as energy values of most dietary components remained remarkably reliable at time 2. It is also speculated that due to the high level of obesity identified by BMI scores patients were too embarrassed to be truthful regarding energy intake. It is possible that the responses to the measure were biased as respondents completed the measure alone rather than sitting face to face with a practitioner (the context in which the measure

has been applied in past assessments). Therefore, future assessment of dietary behaviour with the measure may be more accurate if completed with the assistance of the researcher. A further strategy would be to ask partners to complete the measure on behalf of the patient or at least verify patients' reports.

Physical activity

Responses to the Baecke physical activity questionnaire revealed low levels of intentional physical activity that were consistent with previous research (Ford & Herman, 1995; Hays & Clark, 1999). It is speculated that such low levels were a result of the degree of co-morbidity in the sample. Indeed, many patients suffered with rheumatoid arthritis or circulatory problems. In addition, lower levels of exercise were associated with greater body mass indicating that heavier individuals find effective exercise difficult to perform. The combination of these 'barriers' to exercise was substantial in its impact on patients' activity levels. In addition, there is a possibility that levels of exercise may even have been higher than normal due to the fact that patients were being observed in a prospective study.

It was also apparent from responses that in most cases physical activity in able patients constituted 'gardening', 'walking' or 'housework'. This observation highlights the need for health care professionals to emphasise the importance of regular aerobic physical activity for health benefits in terms of managing diabetes and cardiovascular fitness. Future assessment of physical activity in such a population may benefit from the employment of objective assessment methods such as accelerometers. The major advantage of this method is that it is not influenced by self-report bias. If patients consented to wear accelerometers it would provide accurate feedback with regard to the extent and intensity of their daily activities. The efficacy of accelerometry has been shown in normal and overweight individuals over a 7-day period (Cooper et al, 2000).

Medication

It is clear from the extent that responses to the MARS were positively skewed that patients with diabetes find the process of taking tablets to treat their diabetes to be easier than adhering to dietary restrictions and engaging in physical activity. This observation is consistent with previous work (Glasgow et al, 1997) and is indicative of inherent differences regarding patients' self-efficacy with the disparate demands of the diabetic regimen. The prescription of oral agents in the management of diabetes often occurs once behavioural intervention relating to diet and exercise fails to control blood-glucose levels. Therefore, it is not surprising that patients show greater efficacy in adhering to medication. Furthermore, from the perspective of the social context of adherence it may be easier for a patient to take oral agents with the aid of environmental cues and reminders from concerned partners. However, such limited variance in response to items on the MARS is indicative of over-reporting medication adherence. When validated against objective measures such as pill counts or biochemical methods, self-reporting of medication adherence is highly variable in terms of accuracy (Francis et al, 1969). More accurate adherence with oral medication may also be measured objectively with electronic monitoring techniques (Farmer, 1999).

6.9. Psychological morbidity

The high level of anxiety reported at time 1 yielded a positively skewed distribution of scores, whereas depression scores revealed a distribution more akin to 'normal'. However, scores for depression were still indicative of high levels of 'caseness'. With regard to the high prevalence of anxiety and depression assessed with the HADS, it is a possibility that levels of well-being were partly associated with the high level of co-morbidity in the sample. Indeed, many respondents were elderly (mean age = 67 years) and suffering with a variety of co-morbid conditions. For example, rheumatoid arthritis was a particularly common

complaint (31%). It is also interesting to note that levels of anxiety had significantly decreased at time 2 and levels of depression increased.

Although there is a high level of co-morbidity between anxiety and depression in diabetes patients (Judd et al, 1998; Lloyd et al, 2000) these results support the view that they should be considered as separate states. Nonetheless, it is hypothesised that anxiety may be a pre-cursor of depression. Indeed, those scoring high on the anxiety scale at time 1 may have gone on to develop more symptoms that are characteristic of depression over the study period. To test this hypothesis, a partial correlation was conducted between anxiety (time 1) and depression (time 2) controlling for depression at time 1 which revealed a highly significant association (p <.001). Furthermore, there was an increase in *emotional representations* of diabetes at time 2 which assesses perceptions of fear, anger and depression relating to a diagnosis of diabetes. However, representations of diabetes at time 1 did not emerge as predictors of depression at time 2 (only previous levels of depression predicted depression at time 2). This provides evidence that levels of depression may not be the product of the illness representations of the patient or spouse and thus leaves open the question as to the association between diabetes and depression. It is possible that depression may be a function of the biochemical changes directly due to the illness or its treatment. Possible mechanisms include changes in the effects of catecholamine levels and serotonin concentrations on glucose regulation (Goodnick et al., 1995).

It is, therefore, suggested that patients are reluctant to report states such as depression and anxiety when probed in such a direct manner (i.e., 'I get depressed when I think about my diabetes') as opposed to assessing the symptomatology of morbid states with the more subtle approach of the HADS.

It is also possible that they do not associate depression and anxiety with having diabetes. It must also be considered that patients may have experienced a 'priming' effect with regard to their reports of depressive symptomatology. Indeed, patients may not have considered the psychological effects of living with diabetes until entering the study and these scale items may have introduced a concept that was not salient before participation.

At time 2 it was apparent that patients representations of diabetes at time 1 played a significant role in predicting anxiety measures at time 2. As might be expected, stronger beliefs that the disease is chronic predicted more anxiety whereas a greater understanding of the condition predicted lower levels of anxiety. It is difficult to interpret how stronger *personal control* beliefs lead to a greater likelihood that the patient will suffer with clinically significant anxiety. This finding is counter-intuitive and contradicts previous work that has shown that self-efficacy beliefs are positively associated with a more general assessment of well-being (Eiser et al, 2001). Additionally, in long-standing patients with type 2 diabetes weaker control beliefs were significantly associated with greater anxiety and depression (Wearden et al, 2003). However, these previous studies adopted cross-sectional designs making the direction of causality difficult to interpret.

A finding of particular interest is that experiencing symptoms of high blood-glucose is almost 2.5 times more likely to result in clinically significant levels of anxiety. This finding is a clear demonstration that the perceived *identity* of the condition is directly associated with well-being and acts an unpleasant reminder of the potential consequences of living with high blood-glucose. Finally, partners' representations of the patients' diabetes appear to have little impact once demographic, clinical and patients' representations are controlled for in regression analyses.

6.10. Blood-glucose control

A measure of HbA1c was obtained from 76% of patients to coincide with completion of measures at time 2 to assess metabolic control. As laboratory guidelines indicate that desirable levels should fall between 4-6%, it was clear that, generally, patients were not in reasonable control of their diabetes. The mean score was 7.4% and although slightly less than HbA1c recordings observed in other psychosocial studies of patients with diabetes, 30% of the sample tested had scores of > 8% which approaches the recommended upper level of 8.4% at which the risk of microvascular complications dramatically increases (DCCT Research Group, 1988). These levels are a further indication that although representations of diabetes were in line with medical knowledge, such beliefs did not manifest themselves into tight control of diabetes. Whether glucose control is maintained through self-management behaviours is uncertain as blood-glucose levels may be influenced factors other than adherence. For example, stress is believed to influence hyperglycaemia, although its exact role is unclear (Surwit & Schneider, 1993). However, significant improvements in HbA1c have been found in patients adhering to specific diet related advice in two large prospective trials (Delahanty et al., 1993; UKPDS Group, 1990) and more recently in insulin resistant patients at risk of developing diabetes (Diabetes Prevention Research Group, 2002, Tuomilehto et al, 2001). In addition, a meta-analysis has shown that regular physical activity can reduce HbA1c by 0.7% in type 2 diabetes (Boule et al., 2001).

None of the diabetes representations that predicted blood-glucose control replicated the findings of previous studies reviewed in Chapter 1. These studies have shown that patients' beliefs in *treatment effectiveness, cause* -'own-behaviour' (Hampson et al, 1995) and *control* (Hampson et al, 2000) prospectively predict lower levels of HbA1c, whereas *consequences* and *identity* dimensions were predicted higher levels of HbA1c in a cross-sectional study (Griva et al, 2000). In the present study patients with strong beliefs in an 'external' *cause* of diabetes were in poorer control of their diabetes. It is also noteworthy that partners believing in a

'hereditary' *cause* of diabetes predicted poorer control of the patients' diabetes. Finally, partners holding strong beliefs in the importance of patients' *treatment* to control diabetes predicted better control of diabetes. In general, such mixed findings make it difficult to interpret the nature of the relationship between representations of diabetes and glucose control. However, the present findings suggest that patients absolve themselves from the responsibility of managing their disease as they may perceive the *cause* as beyond their control. Furthermore, patients may view the onset of diabetes as being genetic in origin and not a result of their lifestyle. It appears that partners' representations are implicated in glucose control, however, it should be noted that if HbA1c was measured at both time-points it would have been possible to assess change over the study period and perhaps provide more insight into how patients' and partners' representations are related to changes in glucose control.

6.11. Dyadic adjustment and social support

There was a high level of marital satisfaction among dyads assessed with the DAS and satisfaction remained stable over the study period. Furthermore, the duration of living with a partner approached 36 years suggesting that most dyads were enjoying long relationships. The mean score on the DAS of 28.1 at time 1 compared very favourably with a mean of 25.6 attained in a healthy sample of 196 participants (Hunsley et al, 1995). It is interesting to note that levels of dyadic adjustment in patients were negatively predicted by the duration of the marriage and were greater in patients reporting higher levels of *illness coherence*. In addition, partners with strong beliefs that the patients' 'own behaviour' was a *cause* of diabetes negatively predicted dyadic adjustment. Such results suggest that representations of diabetes have important implications for the marital relationship. Indeed, it would appear that happier relationships are enjoyed by patients in less established relationships who have a better understanding of the condition with partners who do not view the onset of diabetes as being the fault of

the patient. At time 2 patients with stronger *emotional representations* and *cyclical time-line* beliefs were predictive of lower levels of dyadic adjustment. The inverse relationship between *emotional representations* and dyadic adjustment at time 2, however, suggests that patients' relationships suffer as a result of the distress resulting from living with diabetes.

A number of studies have demonstrated a general trend showing that the provision of social support results in favourable outcomes in diabetes management (Glasgow & Toobert, 1988; Garay-Sevilla et al. 1995, MacLean & Lo, 1998; Lo, 1999; Toljamo & Hentinen, 2001; Williams & Bond, 2002). The consistency of this relationship may assist in explaining the extent that partners' representations displayed considerable similarity with those of patients and also impacted on the management of diabetes. The extent that patients and partners were in agreement with regard to their representations of diabetes may be a function of the degree of marital satisfaction in the study sample. It is proposed that patient-partner representations of diabetes are more likely to be shared as a result of the level of communication enjoyed in the marital relationship, which, in turn manifests in higher levels of support and vice-versa. However, in accordance with 'family functioning' theory (Epstein et al., 1978) the course of a chronic disease such as diabetes may impose an excessive load on the capability for the family to adapt and may threaten family stability. Indeed, Garay-Sevilla et al. (1995) demonstrated that adherence to diabetes medication was lower in patients from families exhibiting more rigid patterns of functioning than those with a more flexible outlook. With regard to glucose control, Trief et al, (2001) found marital satisfaction assessed with the DAS predicted less diabetes-specific emotional problems and showed a positive trend in the prediction of HbA1c.

The incidence of psychological morbidity measured in the present patient sample suggests that emotional problems were present (although may not have been directly related to the illness). Therefore, it is possible that dyadic adjustment acts as a buffer against the demands of living with type 2 diabetes and is reflected in

the extent that partners' diabetes representations were associated with patients' management behaviours and glucose control. However, it is unclear whether a poor relationship leads to poor illness adaptation and glucose control or that poor control/adaptation leads to more emotional problems arising from living with the disease. A further issue is that psychological morbidity in partners was not assessed in this study. It is considered, therefore, that the measurement of anxiety and depression in partners may offer insight into the emotional impact that living with a patient with diabetes has on a partner and how partners' representations are associated with adverse outcomes.

A further unresolved issue is the effect of gender in relation to social support, illness representations and self-management behaviours. The findings of Doherty et al. (1983) showed that wives who believed more strongly in the benefits of the therapeutic regimen for hypertension offered greater support to their husbands. In contrast, it has been shown that males fare less well in terms of controlling their diabetes in the presence of satisfactory support (Heitzman & Kaplan, 1984, Kaplan & Hartwell, 1987). It is reiterated that the effects of gender were controlled for in the present study. Although, it was shown that gender was only a significant predictor of higher sugar consumption in male patients (which has implications for metabolic control) it is difficult to make any further comments regarding the influence of gender in the control of diabetes.

It has been shown is that self-efficacy beliefs (one's belief in personal control) are associated with social support and positive diet-related family interactions (Williams & Bond, 2002). In this study the authors claimed support for Bandura's (1977) assertion that social support is a source of efficacy information but does not affect behaviour directly and suggests that social support could be an important source of efficacy information among diabetes patients. Although self-efficacy was not specifically measured in the present study it is argued that the *personal control* dimension of the IPQ-R taps into this construct. It is suggested, therefore, that the

patients' high levels of *personal control* in the present study were a function of the degree of social support they received. It may be that patients demonstrating stronger *personal control* beliefs (as perceived by their partners) receive more support from those partners which in turn reinforce the patients' own control beliefs.

Finally, the forgoing appraisal of marital satisfaction and social support provides support for the findings of previous work such that the execution of good self-management and control of diabetes is most likely to take place within well-functioning relationships (Glasgow & Toobert, 1988; Garay-Sevilla, 1995; MacLean & Lo, 1998; Lo, 1999; Toljamo & Hentinen, 2001; Williams & Bond, 2002).

6.12. Implications for the self-regulatory model

The present research and the findings of previous research examining the illness representations of significant others (reviewed in Chapter 2) has highlighted a number of implications for the self-regulatory model. The first of these concerns coping behaviours and their relationship with illness representations. Much previous research has assessed coping strategies through the employment of questionnaire based tools (i.e., Rutter & Rutter, 2002, Moss-Morris et al, 1996, Helder et al, 2002a, Heijmans, 1998;1999). However, in the present context, it may be more meaningful to conceptualise coping by assessing what patients actually do with regard to their adaptation to a chronic illness. Indeed, it is argued that Leventhal and colleagues refer to coping as the behaviours a patient adopts in response to dealing with a health threat in their original description of the self-regulatory model (1980, 1984). It is, therefore, argued that the extent of adherence to the health behaviours outcomes (diet, activity and medication) in the present study may be viewed as indices of coping behaviour.

A related point concerns the appraisal of coping efforts, which have been largely ignored in previous research with the self-regulatory model. Thus, if adherence behaviours are viewed as being indicative of coping it is also pertinent to examine the appraisal of such behaviours and their relationship with illness representations.

Of particular relevance to the present research is that the appraisal of the efficacy of a chosen behaviour is pertinent to both patients and their partners. In support of this assertion, it was shown that partners' beliefs (in addition to patients' beliefs) were predictive of adherence with different health behaviours at time 1 and time 2 suggesting that partners also 'appraise' the effectiveness of the patients' health behaviours. Furthermore, the representations for which patients and partners demonstrated differences were not repeated when assessed at time 2. Thus, if partners perceived a particular aspect of the patients' treatment as ineffective such beliefs may be conveyed to the patient. In turn, these beliefs may serve to elicit an alternative behaviour or may result in a change of the representation of the patients' illness. With further reference to the original description of the self-regulatory model, it is proposed that the appraisal processes of patients (and significant others) are processed in parallel, such that the appraisal of health behaviours feedback to influence emotional responses to the illness and future coping efforts. An illustration of how partners' representations may be integrated into the SRM can be seen in Figure 6.1. It is suggested that such a framework may be useful in guiding future research with the emphasis on emotional responses and appraisal of the efficacy of health behaviours.

A third point is that there may be scope for the development of a further illness representation dimension to assess the extent that the patient is to blame for the onset or mis-management of their illness. This may be particularly relevant in the context of assessing the impact of 'lifestyle' diseases such as type 2 diabetes or coronary heart disease. Support for the development of this dimension comes

partly from the extent that causal attributions relating to the patients' 'own behaviour' (i.e., diet, weight, lack of exercise) were endorsed by patients and partners alike. Moreover, such a scale may be particularly pertinent in studies assessing the representations of significant others in relation to managing illness.

In addition, it is also considered that the illness representations framework could benefit from further development in the context of diabetes by merging the most salient dimensions measured by the IPQ-R and those pertaining to the PMDI. First, with regard to the IPQ-R, the *personal control* and *emotional representation* sub-scales were the most ubiquitous predictors whereas the *time-line* sub-scales (acute and cyclical) were the least predictive of patient outcomes. In addition, the dimensions of *identity* and the importance of *treatment now* and *future* adapted from the PMDI appeared to augment the control scales of the IPQ-R. Overall, in terms of predictive utility, the findings of previous and present findings discussed earlier indicate that control beliefs are the most salient representations. It is suggested, therefore, that there is support for the control dimensions of the IPQ-R and the PMDI to be operationalised in combination as a multi-dimensional measure of control in chronic disease. In so doing, a more comprehensive assessment of how control beliefs operate with regard to personal and treatment efficacy may be delineated. Specifically, the evidence suggests that not only should a distinction be made between *personal* and *treatment* control but should also distinguish the extent that treatment for a condition is perceived to be important from a temporal perspective (i.e., 'now' and 'future').

With further reference to treatment beliefs and illness representations, Horne and Weinman (2002) have investigated patients' beliefs regarding preventer treatment for asthma beliefs alongside the illness representations of such patients. This work empirically tested an extended self-regulatory model that includes specific treatment beliefs as well as illness representations with the aim of predicting non-adherence. Hierarchical regression analyses showed that non-adherent behaviours

were associated with doubts about the *necessity* of treatment and *concerns* about its potential adverse effects and with more negative perceived *consequences* of illness. The analysis also permitted the relative contribution of illness representations and treatment beliefs in adherence to medication. The authors assert that the relations between illness representations and treatment beliefs provide support for an extended self-regulatory theory that includes treatment beliefs as well as illness representations. By including additional scales to assess the multi-dimensionality of treatment beliefs these findings and those of the present study provide a clear direction for the development of self-regulatory theory in the context of adherence in chronic conditions such as diabetes and asthma.

Finally, there are some points to raise with regard to the inclusion of the measure of *emotional representations* in the IPQ-R. First, it is proposed that the emotional impact of a disease may precede the patients' cognitions regarding its *consequences, control* and *cause* and *identity.* Indeed, it is not known to what extent patients' illness representations are a function of emotional impact of disease or whether the severity of representations induces an emotional response. It is possible that there is a dynamic interplay between emotional responses and illness cognitions that are a feature of fluctuations in the challenges of living with a disease.

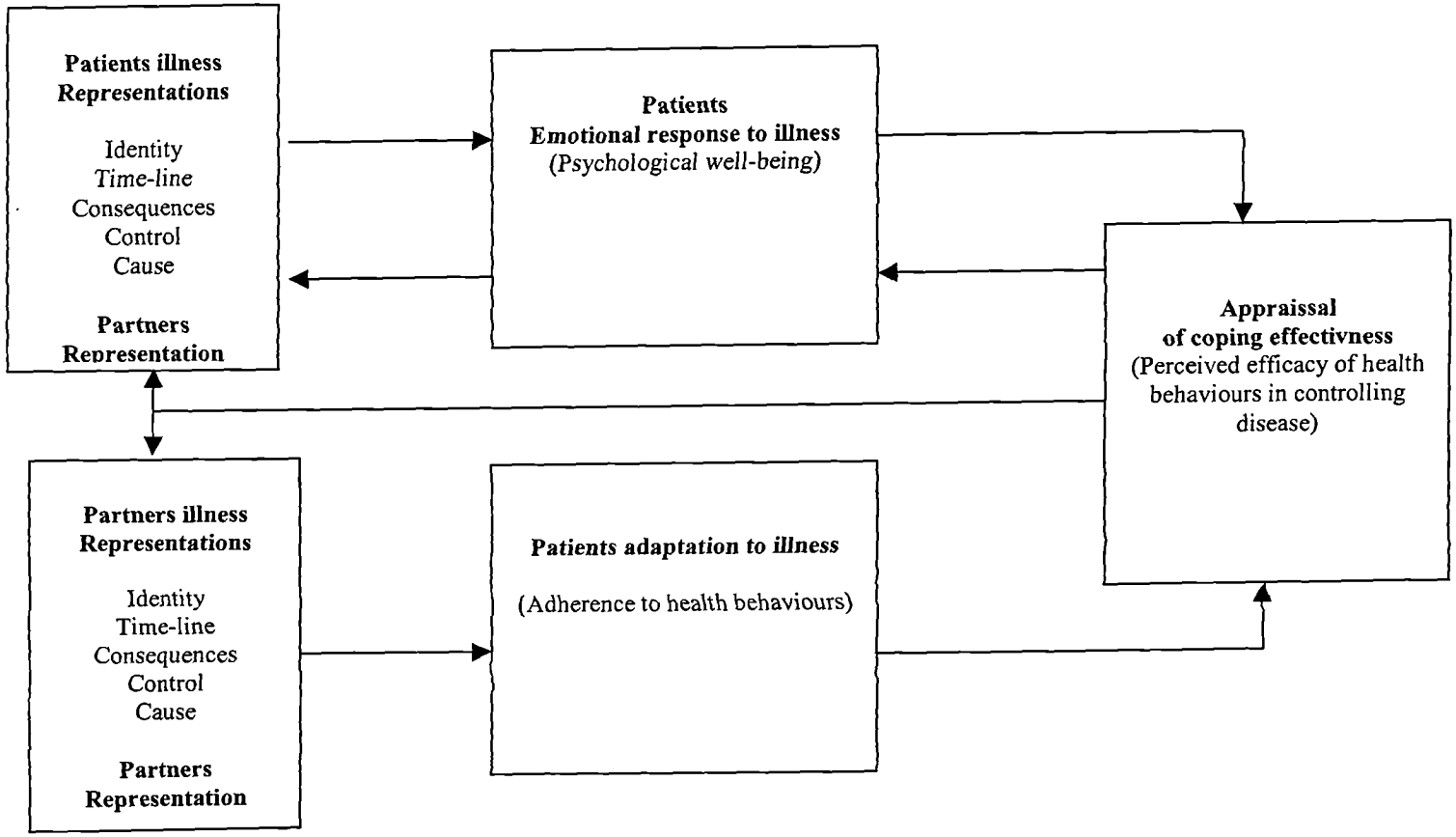
It is also not clear to what extent a disease 'label' triggers *emotional representations* or whether it is the impact on lifestyle and challenges of managing the condition that trigger such emotions. The present sub-scale is therefore considered rudimentary in its conception and application and is worthy of further exploration. Indeed, to assist in delineating these issues a more comprehensive approach is required in which the application of qualitative methods may prove fruitful.

There are two more general issues to raise with regard to illness representations. The first of these concerns the assessment of causal attributions in patients with chronic disease. Although, patients and partners in the present study endorsed

coherent ideas as to the possible causes of diabetes, they were not consistent predictors of patients' self-management behaviours. Indeed, the relative lack of predictive utility in the operationalisation of the *cause* dimension in the present and previous research is indicative of a need for re-evaluating the importance of causal beliefs in the self-regulatory model. It may be argued that this observation, may be a function of differences in how causal attributions are aggregated into 'meaningful' sub-scales using factor analytic techniques (i.e., 'external' and 'internal' causes). Nonetheless, there is a need for disease-specific consistency with regard to the aggregation of causal attributions in future research.

Finally, the present research demonstrated the extent that representations of diabetes are important in predicting self-management behaviours and psychological outcomes. However, although all the dimensions of the IPQ-R were predictive of a range of outcomes in diabetes patients the relationships were often difficult to interpret in the context of the self-regulatory model. This observation emphasises the need for consistency in the operationalisation of disease-specific dimensions of the framework in future research in order to assist in delineating their usefulness. In summary, these findings provide further evidence that refutes the notion that patients conceptualise their illness around the 5 'core 'dimensions of illness representations described by Leventhal and colleagues (1984).

Figure 6.1. The integration of partners' illness representations and relations with appraisal in the self-regulatory model.



6.13. Directions for future work

The findings of the literature review in Chapter 1 and the present study may serve to inform and direct future research on illness representations and chronic disease. Self-regulatory theory essentially describes an individuals' internal schemata and their subsequent relationship with the challenges of coping with and managing a given disease. Thus, it is suggested that individuals' representations provide a schemata or 'profile' that can be utilised to help identify those vulnerable to poor self-management of diabetes and may also be used to inform the development of behavioural interventions. Similarly, an illness representations 'profile' for significant others may also be constructed based on the extent that their representations of a patient's disease are considered to promote adaptive self-care health behaviours. This individualised approach in utilising illness representations has been shown to be beneficial for patients recovering from MI (Petrie et al, 2003). Furthermore, evidence in Chapter 1 demonstrated that patients' representations can influence clinical outcomes (i.e., HbA1c, blood pressure and cholesterol) and subsequent long-term health. It is argued, therefore, that there is a need to examine the amenability of illness representations to change in order to promote patients' physical and psychological adaptation to disease. In Petrie et al's study, patients were randomly assigned to receive either standard care which involved a cardiac rehabilitation nurse and hospital visits and standard MI educational material or three 30-40 minute intervention sessions conducted by a psychologist in addition to the routine educational material. The intervention was individualised based on patients' responses to the IPQ and the findings of previous work by the authors. The earlier work showed that patients' perceptions had important effects on their recovery. Specifically, patients who believed their MI would have more serious long-lasting *consequences* were found to have greater levels of illness related disability and were slower in returning to work (Petrie et al, 1996). In addition, patients who had weaker beliefs in the *control* of their condition were less likely to attend cardiac rehabilitation (Petrie et al, 1996, Cooper et al, 1999). Thus in the delivery of the intervention the authors specifically explored and challenged patients' beliefs

regarding the *control, consequences* and *time-line* of MI. The intervention significantly altered patients' beliefs about their illness particularly relating to the targeted representations of the condition. Prior to leaving hospital, patients who received the intervention had significantly modified their perceptions with regard to how long their illness would last and the personal consequences of the MI on their life, compared to the control group. The intervention, group was also more optimistic than the control group that their illness could be controlled. The intervention had a positive effect on patients' understanding of their MI and their preparedness to leave hospital, the speed that patients returned to work and intentions to attend a rehabilitation programme.

It is proposed that a similar model to that developed by Petrie et al may be used as the foundation of an intervention applied in the context of diabetes management. The scope for such an intervention is supported by the accumulated evidence suggesting that representations of diabetes and its treatment are particularly pertinent in predicting relevant health behaviours in diabetes. For example, by targeting patients' exhibiting beliefs that would not, based on the present evidence, favour adherence to the recommended treatment regimen. Moreover, the findings of the present research have demonstrated that partners' representations of diabetes may be of equal importance in determining self-management behaviours and subsequent glucose-control. Finally, the 12-month follow-up period demonstrated a degree of instability with regard to patients and partners illness representations. This observation supports the view that representations are subject to change throughout the trajectory of the disease suggesting that interventions to manipulate representations should be possible regardless of how long patients have lived with the condition.

Thus illness representations may be important and modifiable factors for intervention in patients with chronic disease who do not demonstrate adequate adherence. Such an approach to the individualisation of interventions in health

promotion may also serve to empower patients in terms of controlling their disease.

It also follows that assessing the representations of partners' of patients with chronic disease may prove fruitful in developing interventions aimed at improving adjustment and self-management of a condition such as diabetes. Indeed, partners may 'minimise' or 'maximise' certain representations which in turn may not favour adherent behaviour in patients (described in detail earlier). Therefore, such 'undesirable' representations could be manipulated with the aid of counselling to elicit representations that would complement and support the patient in managing their disease.

It is speculated that such an intervention will follow the following steps. Dyads in which the partner is experiencing difficulties in the management of the condition (as determined by HbA1c) will be targeted for the intervention. Both parties will be required to attend intervention sessions with a health practitioner with skills in couple counselling. The aim of the sessions will be to address three main issues relating to the delivery of the intervention. First, to identify deficiencies in diabetes knowledge regarding effective management. Second, to challenge the extent that partners or patients 'minimise' or 'maximise' representations which serve as potential barriers to effective self-management. Third, to use a shared-decision making approach to work with dyads to identify ways of improving diet and exercise behaviours. The latter would serve to 1) identify problems experienced in adopting health behaviours; 2) establishing realistic goals for behaviour change and 3) elicit workable strategies to implement the behaviours.

However, it is possible that the efficacy of the described intervention may be limited with regard to the sampling limitations outlined at the start of this chapter. Indeed, it cannot be assumed that all patients with type 2 diabetes will accrue the potential benefits from an intervention of this nature. However, it is asserted that the emphasis on the individualisation of the intervention based on

the illness representations of both parties of the dyad will serve to empower participants which may in turn ease any potential limitations.

It is also speculated that the representations of newly diagnosed patients and partners may fluctuate in the early stages of adjustment to the disease. Indeed, psychological adjustment to the diagnosis may be dependent on how such a diagnosis is communicated to the patient in the context of primary care. Therefore studies are needed to assist in determining patients' adjustment to a new diagnosis and the dynamic nature of illness representations over time. Additionally, there has been little research examining the extent that representations of patients are in agreement with the representations of the health care provider. This proposal may also be extended to examine the extent that representations of partners of patients are in agreement with those of health care provider. This may be another informative area of research relating to the assessment of illness representations in chronic disease such as diabetes. Finally, qualitative approaches in the examination of dyadic representations may provide further insights into how partners' representations of diabetes influence patient behaviours and outcomes with regard to the degree of support provided by partners.

6.14. Final conclusions

The focus of this thesis was to provide an exploratory examination of the role of 'significant others' in the health behaviours of patients with type 2 diabetes. The study was undertaken in the context of the self-regulatory model of illness behaviour and utilised the illness representation framework with the employment of theoretically derived questionnaires. In the process of this prospective study it was demonstrated that, in general, patient-partner dyads share representations of type 2 diabetes and its management. Furthermore, it was shown that some of the diabetes representations of partners were important predictors of the patients' health behaviours over and above the patients' representations of the condition. The findings have made a positive

contribution to the limited literature examining the representations of significant others. This was achieved by validating the usefulness of the assessment of partners' representations in the context of adjustment in chronic disease. In addition, the findings may be useful in informing the development of interventions to improve self-management behaviours in chronic disease. The study has also highlighted some neglected theoretical considerations concerning the operationalisation of the illness representations framework and appraisal processes. Finally, partners' beliefs may impact on patients' management of diabetes by influencing behaviour that would favour better control of the condition.

APPENDICES

Appendix 1: Data extraction sheet for systematic review of illness representations literature

SYSTEMATIC REVIEW OF ILLNESS REPRESENTATIONS IN CHRONIC ILLNESS

DT, AS, 2002

ID No [ ][ ][ ]

Assessor AS (e.g. DT)

Reference: Journal BJHP (e.g. JAMA) Year 2002 (e.g. 1994)

Volume 7 (e.g. 271) Pages 377- 391 (e.g. 1940-1947)

First author RUTTGR, C.L (e.g. Dieppe P)

RESEARCH OBJECTIVE

To explore the relationship between the representation dimensions of IBS, to examine which dimensions predict coping strategies. to examine whether illness reps predict outcome and to evaluate the possible mediating role of coping

Inclusion and exclusion criteria

Participants IBS Sufferers

Medical condition Inflammatory Bowel Syndrome

Outcomes COPING, PSYCHOLOGICAL MORBIDITY, QOL

Study design CROSS-SECTIONAL / QUESTIONNAIRE SURVEY

Model LEVENTHAL SELF-REGULATORY MODEL.

Dimensions tested IPQ IDENTITY, CAUSE, TIMELINE, CONSEQUENCES CURE/CONTROL

Other

NUMBER OF PARTICIPANTS 209 patients
175 female
32 Male
19 68 years M=35

Appendix 2: Study invitation letter from patients' GP

Grange Road Surgery
Bishopsworth
Bristol
BS13 8LD
Tel: 0117 9644343
Fax: 0117 9358422

Branch Surgery
48 Coronation Road
Southville
Bristol
BS3 1AR
Tel : 0117 9661645

Dear Patient,

I would like to tell you about a new study that is being conducted by the University of Bristol as part of the Somerset and Avon Survey of Health (SASH). The SASH Diabetes Study, as it is called, aims to investigate how important people in your life, such as your spouse or partner, influence your diabetes and how you cope with it. The researchers would like to ask both you and your partner questions about your diabetes. This would involve you completing a few questionnaires which will be sent you by post and will include reply-paid envelopes.

If you would like to find out more about this study please send the reply slip below in the pre-paid envelope provided. Please take the time to discuss this study with your partner before making a decision. If you would prefer not to be contacted by the researchers please ignore this letter. Thank you for considering this request.

Yours sincerely,

Dr Simon Bradley

Grange Road Surgery

Reply slip (please return in the pre-paid envelope provided)

I would like to receive further information on the SASH diabetes study

Signature:_____ **Date:**_____

Print Name:_____ **Title:**_____

Address:_____

Post code:_____ **Tel Number:**_____

Appendix 3: Study invitation letter for patients and partners

SOMERSET AND AVON SURVEY OF HEALTH

SASH DIABETES STUDY

SASH Diabetes Study
University of Bristol
Dept of Social Medicine
Canynge Hall
Whiteladies Road
Bristol
BS8 2PR

RESEARCH INTO THE ROLE OF THE PARTNER IN THE HEALTH BEHAVIOURS OF PATIENTS WITH TYPE 2 DIABETES

RESEARCHER: Mr Aidan Searle. Tel: 0117 928 7351 **PROJECT SUPERVISOR: Dr Kav Vedhara. Tel: 0117 928 7243**

Dear Mrs Watts, 14 March 2002

The University of Bristol is carrying out research into diabetes and how people important to you, such as your husband or wife influence your illness. The aim of the study is to examine how you and your partner view your illness and how these views are related to following your doctors' advice in controlling your illness.

The researcher, Mr Aidan Searle, is inviting you and your partner to participate in the study. We have enclosed an information sheet for both you and your partner to read so that you can decide whether or not to participate in the study. All information that you and your partner give will be completely confidential and will be used only for the purposes of the study. If you do both decide to participate we would be very grateful if could both complete the consent forms and questionnaire booklets enclosed. You will also be asked to complete similar questionnaire booklets on two further occasions; at 6 months and 12 months time.

It is necessary for both you and your partner to complete separate consent forms and questionnaires. The consent forms and questionnaires are marked accordingly and separate **FREEPOST** envelopes will be provided for you to return them to us. Please return the questionnaires even if there are some questions you are unable to complete.

If you have any queries about the questionnaire or the study please phone Mr Aidan Searle on 0117 928 7351.

Thank you very much for your help, we appreciate your co-operation.

Yours sincerely,

Stephen Frankel
Professor of Epidemiology and Public Health Medicine
Head of Department

Patientinvite/version3/7/11.00.

Appendix 4: Patient information sheet

SOMERSET AND AVON SURVEY OF HEALTH

SASH DIABETES STUDY

SASH Diabetes Study
University of Bristol
Dept of Social Medicine
Canynge Hall
Whiteladies Road
Bristol
BS8 2PR

INFORMATION SHEET

RESEARCHER: MR AIDAN SEARLE. TEL; 0117 928 7351
PROJECT SUPEVISOR: DR KAV VEDHARA. TEL: 0117 928 7243

RESEARCH INTO THE ROLE OF THE PARTNER IN THE HEALTH BEHAVIOURS OF PATIENTS WITH TYPE 2 DIABETES.

You and your partner are being invited to take part in a research study. Before you decide to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your partner. Please ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?
Many patients with diabetes find it difficult to follow doctor's recommendations for controlling their illness such as dietary advice or taking prescribed medication. Therefore, we are interested in the views of you and your partner towards diabetes so that doctors and other health care workers can better understand the impact of the illness on family life.

Why have we been chosen?
You have been chosen because your GP has informed us that you have a diagnosis of type 2 diabetes and are married or cohabiting with a partner.

Do we have to take part?
It is up to you and your partner to decide whether or not to take part – it is entirely voluntary. If you do both decide to take part you will both be asked to sign a consent form. However, you are both still free to withdraw from the study at any time and without giving a reason. This will in no way affect the treatment you receive as a patient.

What will happen to us if we take part?
If you and your partner decide to take part you will be sent a detailed questionnaire asking questions about your thoughts and attitudes towards diabetes and control of the illness. You and your partner will be asked to complete separate questionnaire booklets; the questionnaire for the diabetic patient will take approximately 45 minutes to complete, the questionnaire for the patient's partner will take approximately 10 minutes to complete. You will both be sent the same questionnaire on two further occasions; 6 months and 12 months after the first time.

Will our taking part in this study be kept confidential?
Your medical records will be examined by members of the research team and all the information you give us will treated with strict confidentiality, it will only be seen by the members of the research team.

Appendix 5: Study consent form for patient

SASH DIABETES STUDY

CONSENT FORM For DIABETIC PATIENT

ID						
DATE						

Centre Number:
Study Number:
Patient Identification Number:

SASH DIABETES STUDY
University of Bristol
Dept of Social Medicine
Canynge Hall, Whiteladies Road.
Bristol, BS8 2PR.

RESEARCH INTO THE ROLE OF THE PARTNER IN THE HEALTH BEHAVIOURS OF PATIENTS WITH TYPE 2 DIABETES.

RESEARCHER: Mr Aidan Searle Tel: 0117 928 7351
PROJECT SUPERVISOR: Dr Kav Vedhara Tel: 0117 928 7243

Please initial box

1. I confirm that I have read and understand the information sheet dated..... (version.....) for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that sections of any of my medical notes may be looked at by responsible individuals from my GP practice where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. ☐

4. I agree to take part in the above study ☐

Name of patient		Date Signature
Researcher		Date Signature

1 for patient; 1 for researcher; 1 to be kept with GP notes

Patientconsent/version3/7/11/00.

Appendix 6: Study consent form for partner

SASH DIABETES STUDY

CONSENT FORM For PARTNER

ID						
DATE						

Centre Number:
Study Number:
Patient Identification Number:

SASH DIABETES STUDY
University of Bristol
Dept of Social Medicine
Canynge Hall, Whiteladies Road
Bristol, BS8 2PR.

RESEARCH INTO THE ROLE OF THE PARTNER IN THE HEALTH BEHAVIOURS OF PATIENTS WITH TYPE 2 DIABETES.

RESEARCHER: Mr Aidan Searle Tel: 0117 928 7351
PROJECT SUPERVISOR: Dr Kav Vedhara Tel: 0117 928 7243

Please initial box

1. I confirm that I have read and understand the information sheet dated..... (version.....) for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I agree to take part in the above study ☐

Please give name of partner:_____

_____	_____	_____
Your name		Date Signature
_____	_____	_____
Researcher		Date Signature

1 for patient; 1 for researcher; 1 to be kept with GP notes

Spouseconsent/version3/7/11/00.

Appendix 7: Reminder letter for participants

SOMERSET AND AVON SURVEY OF HEALTH

SASH DIABETES STUDY

SASH Diabetes Study
University of Bristol
Dept of Social Medicine
Canynge Hall
Whiteladies Road
Bristol BS8 2PR

RESEARCH INTO THE ROLE OF THE PARTNER IN THE HEALTH BEHAVIOURS OF PATIENTS WITH TYPE 2 DIABETES

RESEARCHER: Mr Aidan Searle. Tel: 0117 928 7351

REMINDER

204 St. Johns Lane

Bedminster

BS3 5AR

20 February 2002

Dear Mr Day

You should have recently received in the post some information and questionnaires for you and your partner regarding the above study. We appreciate that you will need to find the time to complete the questionnaires. We would, however, be grateful if you could do this at your earliest convenience. It is important that as many people as possible complete the questionnaires so that we can be sure that the results we obtain accurately reflect the experiences of people with diabetes.

If you already have returned the questionnaires, please ignore this letter and accept our apologies for having troubled you further. If, however, you would like some assistance in completing some or all of the questionnaires, please do not hesitate to contact us on the number above. We would be pleased to assist in any way we can.

Many thanks for considering this request – your help is greatly appreciated. We hope that you will be able to help us with this research and look forward to receiving your completed questionnaires in the near future.

Yours faithfully

Aidan Searle

Researcher

Appendix 8: Illness representations measure – patients

Your thoughts about your Diabetes

Listed below are a number of symptoms that you may or may not experience in relation to your diabetes. Please indicate by circling Yes or No, whether you experience any of these symptoms when your blood glucose is high.

1. Nauseous	Yes	No
2. Depressed	Yes	No
3. Anxious / worried	Yes	No
4. Dizzy / faint	Yes	No
5. Unusually tired	Yes	No
6. Irritable/ Moody	Yes	No
Do you....		
7. Urinate frequently	Yes	No
8. Have blurred vision	Yes	No
9. Have increased thirst	Yes	No
10. Other	Yes	No

Please indicate by circling Yes or No, whether you experience any of these symptoms when your blood glucose is low.

1. Shaky	Yes	No
2. Anxious / worried	Yes	No
3. Hungry	Yes	No
4. Confused	Yes	No
5. Tired	Yes	No
6. Dizzy / faint	Yes	No
7. Irritable / Moody	Yes	No
8. Nauseous	Yes	No
9. Sweaty / chills	Yes	No
10. Headache	Yes	No
11. Other	Yes	No

We are interested in your personal views of how you see your diabetes today.

Please indicate how much you agree or disagree with the following statements about your diabetes.

		STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE
1	My treatment can control my diabetes					
2	My diabetes is a mystery to me					
3	My diabetes will pass quickly					
4	I expect to have diabetes for the rest of my life					
5	My diabetes is a serious condition					
6	My diabetes makes me feel angry					
7	My diabetes does not have much effect on my life					
8	My diabetes strongly affects the way others see me					
9	My diabetes has serious financial consequences					
10	There is a lot which I can do to control my symptoms					
11	My symptoms come and go in cycles					
12	Nothing I do will affect my diabetes					
13	I have the power to influence my diabetes					
14	My diabetes will improve in time					
15	The symptoms of my diabetes are puzzling to me					
16	My diabetes will last for a long time					
17	There is nothing which can help my diabetes					
18	When I think about my diabetes I get upset					
19	My diabetes will last a short time					
20	My diabetes doesn't make any sense to me					
21	I have a clear understanding of my diabetes					
22	The course of my diabetes depends on me					
23	Having diabetes makes me feel anxious					
24	I get depressed when I think about my diabetes					
25	My diabetes has major consequences on my life					
26	I don't understand my diabetes					
27	My diabetes does not worry me					
28	My diabetes is very unpredictable					
29	My diabetes makes me feel afraid					
30	My diabetes can be controlled by my treatment					
31	What I do determines whether my diabetes gets better or worse					
32	The symptoms of my diabetes change a great deal from day to day					
33	My actions will have no effect on the outcome of my diabetes					
34	There is very little that can be done to improve my diabetes					
35	My diabetes is likely to be permanent rather than temporary					
36	My treatment will be effective in managing my diabetes					
37	The negative effects of my diabetes can be prevented by my treatment					
38	My diabetes causes difficulties for those who are close to me					
39	I go through cycles in which my diabetes gets better or worse					

Control of your diabetes

Please indicate the extent to which you feel that the following treatment recommendations are important for controlling your diabetes.

	HOW IMPORTANT ARE THE FOLLOWING FOR CONTROLLING YOUR DIABETES	NOT IMPORTANT 1	2	NOT SURE 3	4	VERY IMPORTANT 5
1	Exercising regularly					
2	Testing blood glucose regularly					
3	Having your cholesterol checked regularly					
4	Having your blood sugar checked regularly					
5	Having regular eye tests					
6	Checking your feet regularly					
7	Eating a diet low in fat and high in fibre					
8	Not eating too many sweet foods					
9	Drinking little or no alcohol					
10	My diabetes medication					
11	Not smoking					
12	Taking diabetes medication as prescribed by your GP					

Please indicate the extent to which you feel that the following treatment recommendations are important for avoiding future complications relating to your diabetes.

	HOW IMPORTANT ARE THE FOLLOWING FOR AVOIDING FUTURE COMPLICATIONS RELATING TO YOUR DIABETES	NOT IMPORTANT 1	2	NOT SURE 3	4	VERY IMPORTANT 5
13	Exercising regularly					
14	Testing blood glucose regularly					
15	Having your cholesterol checked regularly					
16	Having your blood sugar checked regularly					
17	Having regular eye tests					
18	Checking your feet regularly					
19	Eating a diet low in fat and high in fibre					
20	Not eating too many sweet foods					
21	Drinking little or no alcohol					
22	My diabetes treatment					
23	Not smoking					
24	Taking diabetes medication as prescribed by your GP					

Causes of your diabetes

We are interested in what you consider may have contributed to causing your diabetes. As people are very different, there is no correct answer for this question. We are interested in your own views about the factors rather than what others including doctors

or family have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE
1	Stress or worry caused my diabetes					
2	Other people caused my diabetes					
3	A germ or virus caused my diabetes					
4	My weight caused my diabetes					
5	Alcohol caused my diabetes					
6	Smoking caused my diabetes					
7	Hereditary factors (in the family) caused my diabetes					
8	My own behaviour caused my diabetes					
9	Diet or eating habits caused my diabetes					
10	Chance or bad luck caused my diabetes					
11	Poor medical care in my past caused my diabetes					
12	Pollution in the environment caused my diabetes					
13	A lack of exercise caused my diabetes					

Think about what may have caused your diabetes. What do you think were the three most important factors in causing your diabetes? You may use any of the items from the box above, or you may have additional ideas of your own.

The three most important causes were:

1st_____

2nd_____

3rd_____

Appendix 9: Illness representations measure – partners

Your thoughts about your partner's diabetes

Listed below are a number of symptoms that your partner may or may not experience in relation to his / her diabetes. Please indicate by circling Yes or No, whether your partner experiences any of these symptoms when his / her blood glucose is high.

1. Nauseous	Yes	No
2. Depressed	Yes	No
3. Anxious / worried	Yes	No
4. Dizzy / faint	Yes	No
5. Unusually tired	Yes	No
6. Irritable / Moody	Yes	No
Do they....		
7. Urinate frequently	Yes	No
8. Have blurred vision	Yes	No
9. Have increased thirst	Yes	No
10. Other	Yes	No

Please indicate by circling Yes or No, whether your partner experiences any of these symptoms when his / her blood glucose is low.

1. Shaky	Yes	No
2. Anxious / worried	Yes	No
3. Hungry	Yes	No
4. Confused	Yes	No
5. Tired	Yes	No
6. Dizzy / faint	Yes	No
7. Irritable / Moody	Yes	No
8. Nauseous	Yes	No
9. Sweaty / chills	Yes	No
10. Headache	Yes	No
11. Other	Yes	No

We are interested in your personal views of how you see your partner's diabetes today.
Please indicate how much you agree or disagree with the following statements about your partner's diabetes.

		STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE
1	Treatment can control my partner's diabetes					
2	My partner's diabetes is a mystery to him / her					
3	My partner's diabetes will pass quickly					
4	I expect my partner to have diabetes for the rest of his / her life					
5	My partner's diabetes is a serious condition					
6	My partner's diabetes makes him / her feel angry					
7	My partner's diabetes does not have much effect on his / her life					
8	My partner's diabetes strongly affects the way others see him / her					
9	My partner's diabetes has serious financial consequences					
10	There is a lot which my partner can do to control his / her symptoms					
11	My partner's symptoms come and go in cycles					
12	Nothing my partner does will affect his / her diabetes					
13	My partner has the power to influence his / her diabetes					
14	My partner's diabetes will improve in time					
15	The symptoms of my partner's diabetes are puzzling to him / her					
16	My partner's diabetes will last for a long time					
17	There is nothing which can help my partner's diabetes					
18	When my partner thinks about his / her diabetes he / she gets upset					
19	My partner's diabetes will last a short time					
20	My partner's diabetes doesn't make any sense to him / her					
21	My partner has a clear understanding of his / her diabetes					
22	The course of my partner's diabetes depends on him / her					
23	My partner's diabetes makes him / her feel anxious					
24	My partner gets depressed when he / she thinks about their diabetes					
25	My partner's diabetes has major consequences on his / her life					
26	My partner does not understand his /her diabetes					
27	My partner's diabetes does not worry him / her					
28	My partner's diabetes is very unpredictable					
29	My partner's diabetes makes him / her feel afraid					
30	My partner's diabetes can be controlled by treatment					
31	What my partner does determines whether his / her diabetes gets better or worse					
32	The symptoms of my partner's diabetes change a great deal from day to day					
33	My partner's actions will have no effect on the outcome of his / her diabetes					
34	There is very little that can be done to improve my partner's diabetes					
35	My partner's diabetes is likely to be permanent rather than temporary					

37	The negative effects of my partner's diabetes can be prevented by his / her treatment					
38	My partner's diabetes causes difficulties for those who are close to him / her					
39	My partner goes through cycles in which his / her diabetes gets better or worse					

Control of your partner's diabetes

Please indicate the extent to which you feel that the following treatment recommendations are important for controlling your partner's diabetes.

	HOW IMPORTANT ARE THE FOLLOWING FOR CONTROLLING YOUR PARTNER'S DIABETES	NOT IMPORTANT 1	2	NOT SURE 3	4	VERY IMPORT-ANT 5
1	Exercising regularly					
2	Testing blood glucose regularly					
3	Having his / her cholesterol checked regularly					
4	Having his / her blood sugar checked regularly					
5	Having regular eye tests					
6	Checking his / her feet regularly					
7	Eating a diet low in fat and high in fibre					
8	Not eating too many sweet foods					
9	Drinking little or no alcohol					
10	My partner's diabetes medication					
11	Not smoking					
12	Taking diabetes medication as prescribed by his / her GP					

Please indicate the extent to which you feel that the following treatment recommendations are important for avoiding future complications relating to your partner's diabetes.

	HOW IMPORTANT ARE THE FOLLOWING FOR AVOIDING FUTURE COMPLICATIONS RELATING TO YOUR PARTNER'S DIABETES	NOT IMPORTANT 1	2	NOT SURE 3	4	VERY IMPORT-ANT 5
13	Exercising regularly					
14	Testing blood glucose regularly					
15	Having his / her cholesterol checked regularly					
16	Having his / her blood sugar checked regularly					
17	Having regular eye tests					
18	Checking his / her feet regularly					
19	Eating a diet low in fat and high in fibre					
20	Not eating too many sweet foods					
21	Drinking little or no alcohol					
22	My partner's diabetes treatment					
23	Not smoking					
24	Taking diabetes medication as prescribed by his / her GP					

Causes of your partner's diabetes

We are interested in what you consider may have contributed in causing your partner's diabetes. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors rather than what others including doctors or family have suggested to you. Below is a list of possible causes for your partner's illness. Please indicate how much you agree or disagree that they caused your partner's diabetes by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE OR DISAGREE	AGREE	STRONGLY AGREE
1	Stress or worry caused my partner's diabetes					
2	Other people caused my partner's diabetes					
3	A germ or virus caused my partner's diabetes					
4	My partners' weight caused his / her diabetes					
5	Alcohol caused my partner's diabetes					
6	Smoking caused my partner's diabetes					
7	Hereditary factors (in the family) caused my partner's diabetes					
8	My partner's own behaviour caused his / her diabetes					
9	Diet or eating habits caused my partner's diabetes					
10	Chance or bad luck caused my partner's diabetes					
11	Poor medical care in my past caused my partner's diabetes					
12	Pollution in the environment caused my partner's diabetes					
13	A lack of exercise caused my partner's diabetes					

Think about what may have caused your partner's diabetes. What do you think were the three most important factors in causing your partner's diabetes? You may use any of the items from the box above, or you may have additional ideas of your own.

The three most important causes were:

1st_____

2nd_____

3rd_____

Appendix 10: Food Frequency Questionnaire (HEA3)

We are interested in how often you eat certain foods. Please mark your 'average' serving portion size (small, medium or large) for the different foods below, and how often you eat them. If you do not normally eat the food please put a zero (0) in the month column. There is an example shown at the top of the table: This person eats a medium sized portion of 2 slices of bread per day and a large bowl of cereal four times a week.

Food	Typical Medium Serving	Serving Size			How Often		
		S	M	L	Day	Week	Month
Example: Bread	2 medium slices		✓		1		
Example: Cereal	Average bowl / 3 table spoons			✓		4	
Bread / Cereal / Potatoes							
Bread / Toast	2 medium slices						
Breakfast cereal	Average bowl / 3 tablespoons						
Crackers / Crispbread	3 crackers / slices crisp bread						
Bun / roll	1 Bun / roll						
Pitta / chapati	1 small piece (not 'mini')						
Rice / pasta / noodles	Average serving (=6 tablespoons)						
Plantains / green bananas / sweet potatoes	1 plantain or green banana / 2 sweet potatoes						
Potatoes (not chips)	3 egg-sized potatoes						
Fruit / Vegetables							
Vegetables (fresh / frozen / tinned)	Medium serving (2 tablespoons)						
Salad	Medium serving (3 tablespoons)						
Stewed or tinned fruit	Medium serving (3 tablespoon)						
Fresh fruit	1 apple, orange, or banana / small bunch grapes / slice lemon						
Fruit juice	Average glass (160 ml)						
Meat/ Alternatives							

Lean meat / fish / chicken No skin	4 oz / 4 fish fingers (= small pack of playing cards)							
Sausages, burgers, luncheon meat etc.	3 small sausages, 2 burgers, 2 slices of luncheon meat							
All other meat (e.g. beef, chops etc with visible fat, chicken with skin, bacon etc.	4 oz (= small pack of playing cards size)							
Sausage rolls / meat pie	1 individual pie 2 sausage rolls							
Eggs	2 medium							
Beans / lentils / dhal	3 table spoons							
Nuts / peanut butter	1 small bag / table spoon							
Cakes, Puddings,Snacks								
Donut, cake	1 piece							
Pudding, fruit pie, Danish pastry	average bowl / 1 piece							
Biscuits	3 small biscuits							
Chocolate	Small bar							
Ice cream	1 scoop, 1 choc-ice, I king cone							
Crisps, peanuts	1 small bag (25g)							
Sugar								
Sugar	1 teaspoon							
Drinks								
Squash / fizzy drinks	1 can (330ml), average glass (250ml)							
Tea	1 cup							
Coffee	1 cup							
Alcoholic drinks	1 glass wine, ½ pint beer, 1 tot spirits/liqueur (pub measure)							

Fats								
Fried or oily food	e.g., medium portion chips (3/4 cup), 2 fried eggs, 2 rashers fried bacon							
Margarine or butter	1 pat							
Low fat spread	1 pat							
Cooking oil / fat / ghee	1 level tablespoon							
Mayonnaise / oily salad dressing	1 level tablespoon							
Milk and Dairy								
Full fat milk	1/3 pint (200ml)							
Semi-skimmed milk	1/3 pint (200ml)							
Skimmed milk	1/3 pint (200ml)							
Cheese	Small matchbox							
Yoghurt / cottage cheese / fromage frais	Small pot							

Additional questions: Please answer the following questions by circling Yes or No.

1) Do you usually use wholemeal / high fibre / granary bread? Yes No

If yes, please specify type_____

2) Do you use a high fibre breakfast cereal?

Eg. Alpen, muesli, allbran, Jordan's crunchy, shredded wheat,

weetabix, porridge oats, shreddies, fruit n' fibre Yes No

If yes, please specify type: _____

3a) Do you usually eat Wholegrain rice? Yes No

3b) Do you usually eat Wholewheat pasta? Yes No

3c) Do you usually eat Potatoes with skin? Yes No

4 a) Do you use low fat spread, low fat cheese or low fat yoghurt? Yes No

b) If yes, please circle whichever you normally eat / use:

			Specify type
I) Low fat hard cheese	Yes	No	_____
II) Low fat soft cheese	Yes	No	_____
III) Low fat yoghurt	Yes	No	_____

IV) Low fat spread Yes No _____

V) Very low fat spread Yes No _____

5) What sort of oil / fat do you usually use for frying? (please circle one only)

I) Lard / dripping / butter or ghee Yes

II) Blended vegetable oil Yes

III) Polyunsaturated oil (e.g., Sunflower oil) Yes

IV) Monounsaturated oil (e.g., Olive, nut oil) Yes

6) What kind of spreading fat do you usually use? (please circle one only)

I) Butter Yes

II) Ordinary margarine Yes

III) Polyunsaturated margarine (e.g., Sunflower) Yes

IV) Monounsaturated margarine (e.g., Olive, rapeseed) Yes

V) Low fat spread (e.g., Gold, Delight) Yes

IV) Very low fat spread (e.g., Gold lowest) Yes

Appendix 11: Scales from Baecke physical activity questionnaire

Exercise Questionnaire

1) Do you play sport or engage in a particular exercise? Yes / No

If yes:

Which sport / exercise do you do most frequently?_____

How many hours a week?

less than 1 1 - 2 2 - 3 3 - 4 more than 4

How many months a year?

less than 1 1 – 3 4 – 6 7 – 9 more than 9

Do you play any other sport or exercise? Yes / No

If yes:

Please name the sport / exercise_____

How many hours a week?

less than 1 1 - 2 2 - 3 3 - 4 more than 4

How many months a year?

less than 1 1 – 3 4 – 6 7 – 9 more than 9

2) In comparison with others my own age I think my physical activity during leisure time is;

much more more the sameless much less

3) During leisure time I sweat;

very often often sometimes seldom never

4) During leisure time I play sport;

never seldom sometimes often very often

5) During leisure time I watch television;

never seldom sometimes often very often

6) During leisure time I walk

never seldom sometimes often very often

7) During leisure time I cycle;

never seldom sometimes often very often

8) How many minutes do you walk and / or cycle per day to and from work, shops, visiting friend's etc.

less than 5 5 – 15 15 – 30 30-45 more than 45

Appendix 12: Medication adherence scale (MARS)

Your diabetes medicines

We would like to ask you a few questions about how you use your diabetes medicines.

Many people find a way of using their medicines which suits them. This may differ from the instructions on the label or from what their doctor has said.

Here are some ways in which people have said that they use their medicines for each of the statements, please tick the box which best applies to you.

		Always true	Often true	Sometimes true	Rarely True	Never true
1	I avoid using my medicines if I can					
2	I forget to take my medicines					
3	I alter the dose of my medicines					
4	I stop taking my medicines for a while					
5	I decide to miss out a dose					
6	I take less than instructed					

Appendix 13: Hospital Anxiety and Depression Scale

Your Emotions

We are aware that emotions play an important part in maintaining health. This questionnaire is designed to help us know how you feel. Read each item and place a tick opposite the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

1. I feel tense or 'wound up':.....	Most of the time
.....	A lot of the time
.....	Time to time, occasionally
.....	Not at all
2. I feel as if I am slowed down:.....	Nearly all the time
.....	Very often
.....	Sometimes
.....	Not at all
3. I still enjoy the things I used to enjoy:.....	Definitely as much
.....	Not quite as much
.....	Only a little
.....	Hardly at all
4. I get a sort of frightened feeling like butterflies in the stomach:.....	Not at all
.....	Occasionally
.....	Quite often
.....	Very often
5. I get a sort of frightened feeling as if something awful is going to happen:.....	Very definitely and quite badly
.....	Yes, but not too badly
.....	A little, but it doesn't worry me
.....	Not at all
6. I have lost interest in my appearance:.....	Definitely
.....	I don't take so much care as I should
.....	I may not take as quite as much care
.....	I take just as much care as ever

7. I can laugh and see the funny side of things:..... As much as I always could
..... Not quite so much now
..... Definitely not so much now
..... Not at all

8. I feel restless as if I have to be on the move:..... Very much indeed
..... Quite a lot
..... Not very much
..... Not at all

9. Worrying thoughts go through my mind:..... A great deal of the time
..... A lot of the time
..... From time to time, not to often
..... Only occasionally

10. I look forward with enjoyment to things:..... As much as I ever did
..... Rather less than I used to
..... Definitely less than I used to
..... Hardly at all

11. I feel cheerful:..... Not at all
..... . Not often
..... . Sometimes
..... Most of the time

12. I get sudden feelings of panic:..... Very often indeed
..... Quite often
..... Not very often
..... Not at all

13. I can sit at ease and feel relaxed:..... . Definitely
..... Usually
..... Not often
..... Not at all

14. I can enjoy a good book, radio or TV programme:..... Often
..... Sometimes
..... Not often
..... Very seldom

Appendix 14: Dyadic Adjustment Scale

Your Relationship

Most people have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

	Always agree	Almost always agree	Occasionally disagree	Frequently disagree	Almost always disagree	Always disagree
Philosophy of life						
Aims, goals and things considered to be important						
Amount of time spent together						
	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
Have a stimulating change of ideas						
Calmly discuss something						
Work together on a project						

The numbers on the line below represent different degrees of happiness in your relationship. The middle point, 'Happy' (3), represents the degree of happiness of most relationships.

Please circle the number which best describes the degree of happiness, all things considered, of your relationship.

0	1	2	3	4	5	6
Extremely unhappy	Fairly unhappy	A little happy	Happy	Very happy	Extremely happy	Perfect

Appendix 15: Letter to patients at follow-up and request for blood sample

SOMERSET AND AVON SURVEY OF HEALTH

SASH DIABETES STUDY

SASH Diabetes Study
University of Bristol
Dept of Social Medicine
Canynge Hall
Whiteladies Road
Bristol
BS8 2PR

RESEARCH INTO THE ROLE OF THE PARTNER IN THE HEALTH BEHAVIOURS OF PATIENTS WITH TYPE 2 DIABETES

RESEARCHER: Mr Aidan Searle. Tel: 0117 928 7351
PROJECT SUPERVISOR: Dr Kav Vedhara. Tel: 0117 928 7243

Dear

I am pleased to be able to tell you that we have now entered the final phase of this research project. We have greatly appreciated your cooperation with our work so far.

For this final stage we would like you to help us with two things:

1. As before, we enclose questionnaires for you and your partner to complete. These ask about your beliefs about your diabetes and some of the behaviours you may have been asked to change, or have considered changing since you were diagnosed.

2. We would also like to determine how well you are managing your diabetes at this time. To do this we simply need to take one small blood sample from you. This blood sample will give us an indication of how well patients manage their diabetes and will help us to develop ways of assisting patients with blood glucose control.

If you agree to having this blood sample taken, we will ask you to attend our clinic at Weston General Hospital. The blood sample will be taken by an experienced nurse. It is emphasised that the risks associated with taking blood samples are minimal (i.e., some individuals may experience bruising and discomfort). We will also be able to provide travelling expenses or provide transport if necessary for you to attend this appointment.

I would be very grateful if you could consider whether you would be willing to provide us with a blood sample for the last stage of the study. I shall call you within the next few days to discuss the blood test with you and, if you are willing, arrange a time for you to visit the centre to give this blood sample. In the meantime if you have any queries please contact me on 0117 928 7351. (I can call you back).

Thank you once again for all your help with our work. I shall look forward to speaking to you within the next few days.

Yours sincerely,

Aidan Searle (Researcher)

HbA1C/version 2/ 25.6.02

Appendix 16: Consent form for blood sample (HbA1c)

SASH DIABETES STUDY

CONSENT FORM for Blood Test

ID						
DATE						

Centre: BRI

SASH DIABETES STUDY
University of Bristol
Dept of Social Medicine
Canynge Hall
Whiteladies Road.
Bristol, BS8 2PR.

RESEARCH INTO THE ROLE OF THE PARTNER IN THE HEALTH BEHAVIOURS OF PATIENTS WITH TYPE 2 DIABETES.

RESEARCHER: Mr Aidan Searle Tel: 0117 928 7351
PROJECT SUPERVISOR: Dr Kav Vedhara Tel: 0117 928 7243

I agree to have a blood sample taken for analysis of Hba1c to measure my blood glucose control for the purpose of the above study.

Name of patient		Date Signature
Researcher		Date Signature

HbalcConsent11/11/2002

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